Yorkshire Wolds and Coast Primary Care Trust,
Scarborough, Whitby and Ryedale Primary Care Trust,
Scarborough and North East Yorkshire Healthcare NHS Trust

Action On Neurology
GPwSI Headache Clinic Pilot Site

Final report

R. Davis
Headache Clinic Project Manager
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With thanks to all the individuals who have worked on and supported the headache clinic

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1. Executive summary

Why was the project undertaken?
The project was undertaken because it was recognised that there is limited provision of Neurology services in the Scarborough area and that the patient was not always seeing the most appropriate specialist or receiving the most relevant care. There were long waits for patients with symptoms of headache and consultants identified that they had limited time and resources to spend with these patients. It was therefore identified that these patients could be diagnosed and managed more effectively in primary care by a GP with Special Interest (GPwSI) and specialist nurse.

What improvements have been made and how does this fit into the local and national priorities?
A specific service for patients with headache has been developed where patients are assessed and diagnosed by a GPwSI and given an opportunity to receive further support by a specialist nurse. Improvements have therefore included shorter waiting times, quicker access to diagnostic tests and improved access to specialist staff. The development of the clinic fits within the National Service Framework (NSF) for Long Term Conditions and the project has shown that the diagnosis and management of headache conditions can be provided by specialist primary care staff. The clinic has therefore reduced the number of referrals for headache symptoms to secondary care.

What are the additional costs of continuing to provide the new/revised service?
The main costs include staff costs for the GPwSI, Specialist Nurse and outpatient and administration staff. There are also general costs for clinic space and administration. Costing has been given for additional CT scans over and above the agreed service level agreement although findings show that less diagnostic tests were requested than expected.

What have been the limitations and what still needs to be improved?
The pilot project has been funded for 1 year only and so there has been a limit to what can be achieved during this time. It is however recognised that further work is needed to evaluate the long term clinical effect of the management plans on patient's symptoms and that a greater emphasis should be placed on GP education. The project would also have benefited from developing clearer job descriptions and training packages for both the GPwSI and Nurse Specialist. Finally further data analysis could have been done on evaluating the number of diagnostic requests made by the GPwSI in comparison to secondary care professionals and further revisions were in progress on the management plans that have been produced.

2. Background

2.1 *Action On* Neurology
The national *Action On* Neurology programme was established by the Modernisation Agency and provided funding for pilot programmes from January 2004 to March 2005 to develop and test new methods of service design and delivery.

This opportunity allowed local health communities to develop ideas to address local issues and to try new methods of service delivery without causing major disruption. *Action On* Neurology invited Trusts / health communities to bid for funding and of these eight pilot sites were chosen. Yorkshire Wolds and Coast PCT was awarded £75,000 by *Action On* to develop the Headache clinic in partnership with Scarborough, Whitby & Ryedale PCT. Support for the project was obtained from local

clinicians, executive representatives, Scarborough and North East Yorkshire NHS Trust and the strategic health authority. As one of the eight pilot sites guidance and support has been provided by the national *Action On* team throughout the period of the project and there has been the opportunity to share learning and experience with the other sites.

2.2 Review of service provision prior to the commencement of the pilot project

For patients in the Yorkshire Wolds and Coast PCT and Scarborough Whitby and Ryedale PCT areas, options for referring patients with symptoms of headache include:

- Neurologist at York General Hospital
- Headache clinic at York General Hospital run by a GPwSI
- Neurologist at Hull Royal Infirmary
- Headache Clinic at Hull Royal Infirmary run by a Consultant Neurologist
- Visiting Neurologist clinic at Whitby (from James Cook University Hospital, Middlesborough)
- Visiting Neurologist clinic at Scarborough (from Hull Royal Infirmary)
- Consultant General Physician at Scarborough

Patients that were referred to Scarborough were not necessarily being seen by the most appropriate specialist or were waiting a considerable length of time to be seen. The GPwSI clinic was therefore felt by clinicians and service managers to be a possible solution to these issues and it was identified that the majority of patients referred for symptoms of headache could be effectively managed by a GPwSI. Patients had traditionally travelled quite considerable distances to major District General Hospitals for access to neurology services and the GPwSI clinic would therefore offer the potential to provide more localised patient care and reduce waiting list times. This would free up time for the Consultant Neurologist and Consultant General Physician to see more complex cases but would also allow for more time to be spent with those suffering from headache. Local GPs also identified that although the existing service provision was good the long waiting times were of concern as many patients with regular headache symptoms often fear that the cause is something more sinister. The decision was therefore made to make the clinic rapid access to ensure that patients would receive a diagnosis within a set period of time.

A survey of local GPs identified that many were only fairly confident when managing a patient with headache and that they were not always clear on what, if any information had been given to their patient. One of the aims of the project was therefore to assist both GPs and patients in understanding and managing headache symptoms more effectively. It was also recognised that after diagnosis and with some guidance many GPs would be able to manage the patient's headache thus preventing unnecessary follow ups. However it was also noted that if necessary the nurse specialist could provide further support by telephone.

National data indicates that approximately 25% of referrals to neurology services are for symptoms of headache and a baseline survey which analysed case notes from clinics held by both the visiting Consultant Neurologists and the local General Physician was conducted for clinic lists held in March and April. Case notes were analysed for diagnosis to ascertain if patients could have been seen in the GPwSI clinic instead. Of 15 lists reviewed 113 case-notes were analysed and 18 were found with a diagnosis of headache. This equates to 16% of referrals which could have be

seen by a GPwSI but who at present were being seen by either a visiting Neurologist or by the Consultant General Physician.

In June the mean waiting times at Scarborough General Hospital were:
For a routine outpatient appointment:

- Neurologists 11 weeks
- Consultant General Physician14 weeks

For a CT scan: 11 weeks

For a follow up appointment:

- Neurologists 20 weeks
- Consultant General Physician12 weeks

This data therefore indicates that the overall patient pathway took several months from referral to diagnosis and from referral to treatment.

3 Aims of the project

The project identified the potential opportunities of a GPwSI clinic as above but it was also recognised that the GP and patient may need further support once they have been provided with a management plan. In addition to employing a GPwSI the project also aimed to recruit a specialist nurse who would be a point of contact for management queries. The nurse was to be employed on a 6 month secondment and it was hoped that the role would also offer the potential to add further capacity to the clinic in the future.

In summary the key aims of the project were to:

- Improve access for patients presenting with headache
- Ensure timely and appropriate assessments including specialised investigations, diagnosis and management
- Improve response times for first appointment and investigation
- Ensure that the patient is seen by the most appropriate specialist
- Provide a more defined referral pathway for patients suffering from headache
- Develop referral guidelines across the two PCT areas
- Improve patient satisfaction and provide more detailed information on their condition via patient information leaflets
- Improve GP awareness and confidence regarding headache diagnosis and management via GP management plans
- Develop the role of the GPwSI and Specialist Nurse in Headache

4 Service development/ redesign

4.1 Project Initiation

The development of a project initiation document (PID) laid out the proposed aims and objectives of the service and the timescale involved. The project was also supported by a board and planning group made up of commissioners from the PCT, clinicians, service managers, service redesign leads, strategic health authority representatives and patient representatives.

In support of the PID further information was also developed on the staff/kit and clinical network needed for the clinic to become operational. (See appendix 1)

4.2 Process of redesign

In order to facilitate the development and evaluation of the new service, service improvement tools and techniques were utilised including process mapping of the existing service and the proposed service (appendices 2 and 3). The process map of the proposed service was revisited several times so that progress could be monitored and areas highlighted if further work was needed. Capacity and demand methods were also utilised once the new clinic was established.

To ensure that the project could be evaluated efficiently data was collected by various methods. This included staff questionnaires, patient questionnaires and an audit of referrals. Data was also collected on different measures including waiting times, clinic efficiency and clinical diagnosis.

4.3 Timescale for service redesign

The timeframe for planning and developing the new service was approximately 15 months as funding from *Action On* was provided from January 04 to March 05. However considerable investigative work had been done before this time.

The GPwSI and project manager were recruited in April and May and the clinic began on the 27th May 2004. The GPwSI that was recruited needed very little further training as having worked for 3.5 years as a clinical assistant in Neurology, sufficient skills and knowledge had already been acquired around the diagnosis and management of headache. For other project timescales please refer to the Gnatt chart (see appendix 4).

4.4 Patient pathway

Positive changes to the patient pathway include a more defined pathway for headache patients allowing the direct referral into the clinic by GPs. By delivering a service purely for patients with headache it has been possible to reduce the overall time for the patient pathway. By delivering care this way it has also been possible to ensure that patients are informed of their follow up appointment date before they leave the clinic and the diagnostic test is provided within a certain timeframe.

The target from referral to 1st appointment was 2 weeks and from 1st appointment to follow up was 6 weeks (in which time investigations if needed would be done). However it was identified that most patients with symptoms of headache can be diagnosed without the need for further investigation and so can be diagnosed during the 1st appointment.

Patients are recommended to revisit their GP 2 weeks after their GPwSI consultation so their management plan can be actioned. The whole patient pathway should therefore take no longer than 8 weeks.

If additional support is needed for patients with complicated management, for example patients with Medication Overuse Headache, this support is provided by the Specialist Nurse over the telephone. GPs and Patients can also contact the specialist nurse if they have any other queries.

The clinical parameters used were those detailed in the Department of Health guidelines for the appointment of a GPwSI headache and all GPs were provided with a copy of the adapted referral guidelines. (Appendix 5 & 6) A referral proforma was also developed which enabled GPs to fax their referral directly to the clinic. (Appendix 7)

4.5 Staff development

Although the clinic aimed to develop the roles of both GPwSI and the Specialist nurse no formal training documentation was developed. This was because the GP had previously been working as a clinical assistant in Neurology and had considerable experience and expertise in the required area. Clinical support was provided by the Consultant General Physician at Scarborough Hospital when and if needed.

It is recognised that benefit would have been gained by ensuring protected learning time for the nurse specialist and that the lack of any documented training plan for both the GPwSI and Nurse Specialist roles was a considerable short fall in the project. In addition to this the nurse was also only employed for the second half of the project when in hindsight considerable advantages could have been gained had the nurse been employed for the full length of the project.

The decision to employ a nurse specialist as well as a GPwSI has however shown benefits to the patient as the role has enabled**:**

- Greater discussion about the patients understanding of the diagnosis & suggested management plan
- Time for the client to express concerns, worries and ask questions
- More detailed discussion about proposed medication use– acute & prophylactic treatment
- The opportunity to carry out a lifestyle assessment –using listening and negotiating skills to understand the patients lifestyle and agree a process of change necessary to achieve improvement in the headache profile
- Partnership working with the client to agree a preparation and action plan for the withdrawal of medication (medication overuse headache)
- Patients requiring extra support to have follow up
- Onward referral and communication with other healthcare professionals and specialities such as a physical activity co-ordinator and smoking cessation therapist.

5 Benefit Realisations

5.1 Data collection relating to new ways of working

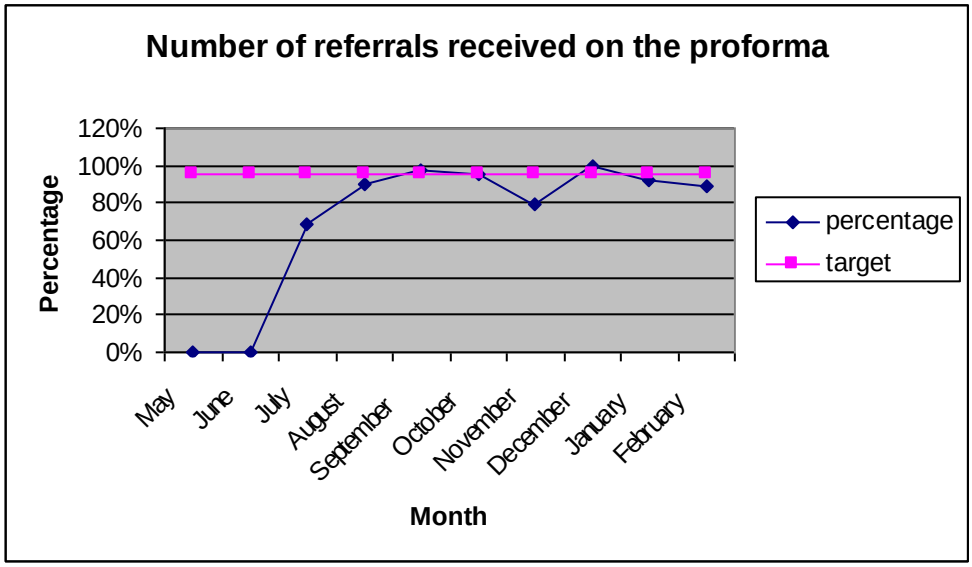
The data for the new clinic was collected manually by the medical secretary who completed a data collection form and a spreadsheet. The form included the:

- name of the referring GP and practice
- time between referral and first appointment
- time from 1st appointment and diagnostic test (if requested)
- time between 1st appointment and follow up
- diagnostic outcome
- management plan provision

This data was collected so that a number of output measures could be developed to assist in the project evaluation. These measures have been included in the sections below.

5.2 System benefits

Number of referrals received on the proforma
In order to provide a more defined referral pathway that was also rapid access a proforma was developed. The target set was that 95% of the total number of referrals made used the correct proforma by September 2004.



The clinic became operational on 27th May 2004 and the first two months were allocated to patients on the Scarborough clinic list. These referrals were therefore transferred across from existing waiting lists and were not on the correct proforma. GPs were informed of and started referring to the clinic in July and overall 81% have used the profoma, however not all were completed adequately. The local medical council have also recently developed policy due to the number of referral proformas (for all specialities) that are now in circulation. This policy indicates that GPs can use proformas if they so wish but that a traditional GP letter should also be accepted as a suitable referral.

A reduction in referral for headache to Scarborough Neurologists /Consultant Physician
The project aimed to reduce the number of referrals for headache to the Neurology service at Scarborough thus freeing up Consultant time to see more complex cases. The Target was a 90% reduction in the total number of patients referred to the Neurology service at Scarborough Hospital for symptoms of headache by March 2005.

An analysis of case notes from clinics held by both the visiting consultant Neurologists and the local General Physician was conducted for clinic lists held in March and April to assess the baseline position. The same process was then done for clinics held in September and October. Case notes were analysed for diagnosis to ascertain if patients could have been seen in the GPwSI clinic instead.

Referrals to	Month	Number of lists reviewed	Number of case notes reviewed	Number of headache diagnosis	% headache diagnosis
Scarborough	March/April	15	113	18	16%
Scarborough	September/October	18	107	9	8%

Early anecdotal evidence given when the clinic was first established suggested that there had been a large decrease in the number of referrals for headache to Scarborough. The data collected in September/October however does suggest that referrals for headache are still being seen at Scarborough Hospital although the number of referrals for headache has been reduced by 50%. There has been no effect on the waiting times for either the Neurologist or the General Physician at Scarborough Hospital.

Capacity
When the clinic was first established slots were allocated for 6 new patients and 6 follow up patients in one 4 hour programmed activity (12 slots). The follow up ratio was therefore estimated at 1:1

GPwSI sessions	Patient slots		
	Scheduled slots	New patient appointments	Follow up appointments
41	492	246	246

Ongoing capacity and demand analysis in the clinic indicated that slots were not being utilised effectively as the majority of patients were being discharged after their first appointment. Therefore the clinic ratio was changed in October to 7 new patients and 3 follow up patients in a 4 hour programmed activity (10 slots). It was also apparent that clinic appointments were running over and that when surveyed some patients felt that a 20 minutes new patient appointment and a 10 minute follow up appointment was too short.

The employment of the nurse specialist provided the opportunity for patients (new and follow up) to receive an additional 20 minutes with a health care professional and increased the total time for a new appointment to 40 minutes and for a follow up to 30 minutes. The nurse also provided additional patient contact as necessary via telephone contact once the patient was discharged from the clinic.

Using the revised clinic ratio the clinic therefore has the capacity for:

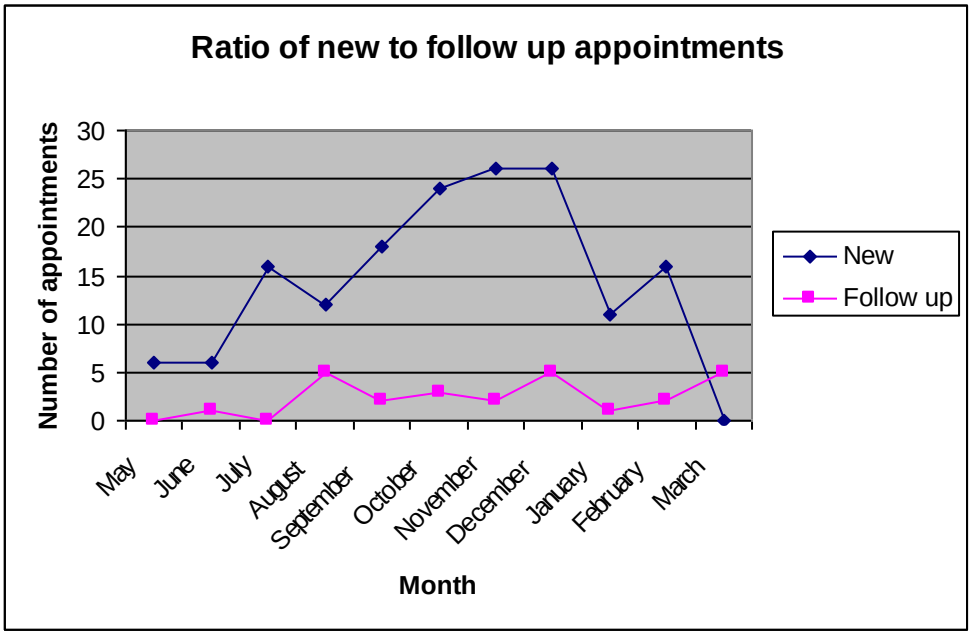
GPwSI sessions	Patient slots		
	Scheduled slots	New patient appointments	Follow up appointments
41	410	287	123

A final analysis at the end of the project indicated that all new patient slots were being filled but that there was still capacity within the follow up slots. However clinics when full would often still run over time. A further recommendation would be that the clinic ratio is amended to 2 follow up per week and then monitored again using capacity and demand.

Efficient clinic utilisation

Ratio of new to follow up appointments

Annual leave was taken in the months of August, September, January and March and this reduced the capacity of new appointments. Additional new patient appointment slots were generated in September when it was recognised that less follow ups were being seen than allocated slots (see capacity above.) New referrals were stopped at the end of February to ensure that all patients were completely through the system by the time the clinic closed.



PCT split

161 new referrals were seen between May-March, of this 59% (95) have been referred by Scarborough, Whitby & Ryedale GPs while Yorkshire Wolds and Coast GPs referred 40% (64) new patients. 1% (2) patients were inter-hospital referrals. The division between the 2 PCT areas is as follows:

Scarborough, Whitby & Ryedale PCT

	May	June	July	August	Sept	Oct	Nov	Dec	Jan	Feb	March	Total
Total Appointment	**5**	**6**	**8**	**10**	**11**	**20**	**15**	**21**	**6**	**9**	**3**	**114**
First Appointment	5	5	8	7	8	17	13	17	6	9	0	95
Follow Ups	0	1	0	3	3	3	2	4	0	0	3	19

Yorkshire Wolds and Coast PCT

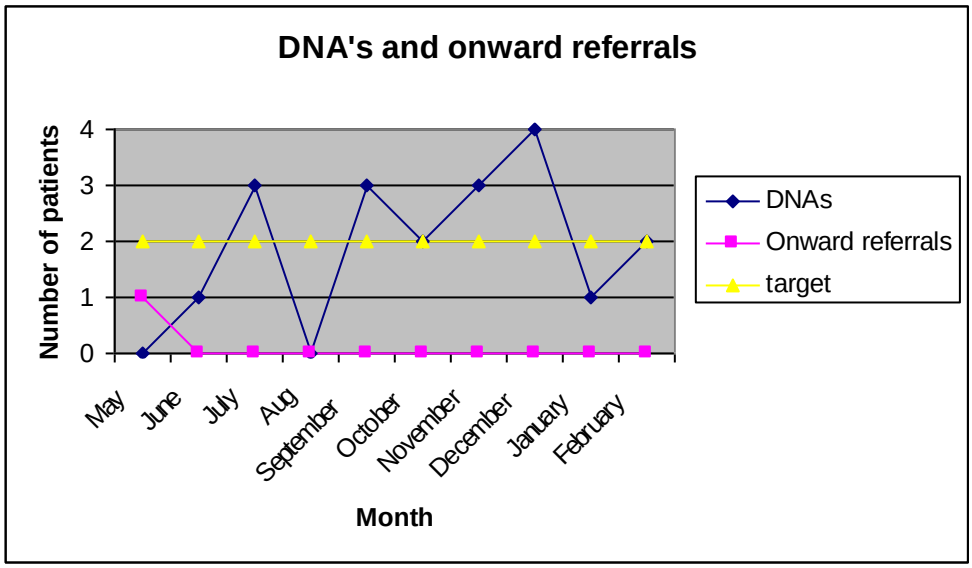
	May	June	July	August	Sept	Oct	Nov	Dec	Jan	Feb	March	Total
Total Appointment	**1**	**1**	**8**	**7**	**8**	**7**	**13**	**11**	**6**	**9**	**2**	**73**
First Appointment	1	1	8	5	8	7	13	9	5	7	0	64
Follow Ups	0	0	0	2	0	0	0	2	1	2	2	9

The geographical distribution of referrals was mainly centred around the Scarborough catchment area although take up can be seen to be as far afield as

Pickering, Whitby, Hedon and Withernsea. The geographical distribution of referrals can be found in appendix 8

Number of DNAs (Did Not Attends) and Onward referrals

The number of DNAs and patients being referred onto another specialist were recorded and if patients did not attend they were later asked by telephone to record a reason.



In total 11% (19/180 patients referred) DNA'd and the reasons given were that they simply forgot or that the time or day was not suitable for them. An increase in DNA's was seen in December after sickness caused a clinic to be cancelled at the end of November and appointments were therefore rescheduled. Only 1 patient was referred onto another specialist (diagnosed with temporal arteritis)

Number of inappropriate referrals

A review of the referrals was undertaken by clinical staff between October to mid December 2004 and 10 lists were analysed. Patients were identified as being inappropriate on attendance at the clinic if:

a) The headache had gone or symptoms were much better
b) Symptoms settled without treatment
c) Patient already investigated by secondary care
d) Patient presents with classical presentation – diagnosis clear, no need for expert opinion
e) Already receiving correct treatment

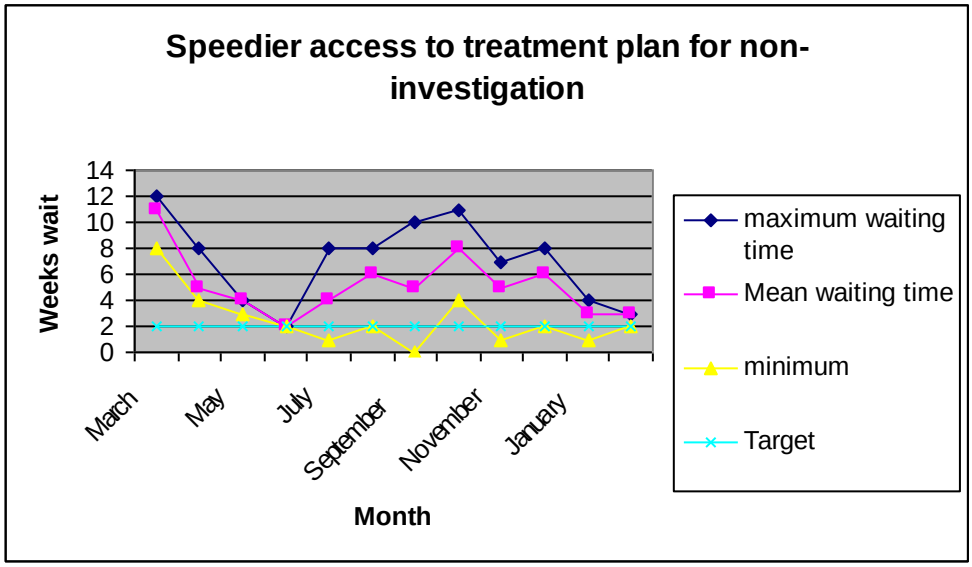
Of the 65 patients given an appointment during this time period 18% (12) were recorded as being inappropriate and it was recognised that some GPs may benefit from further education to ensure that they understand the referral guidelines and purpose of the clinic.

5.3 Patient experience/opinion

The patient experience was evaluated via a clinic questionnaire but information can also be presented by the access times to 1st appointment, diagnostic tests and treatment plans.

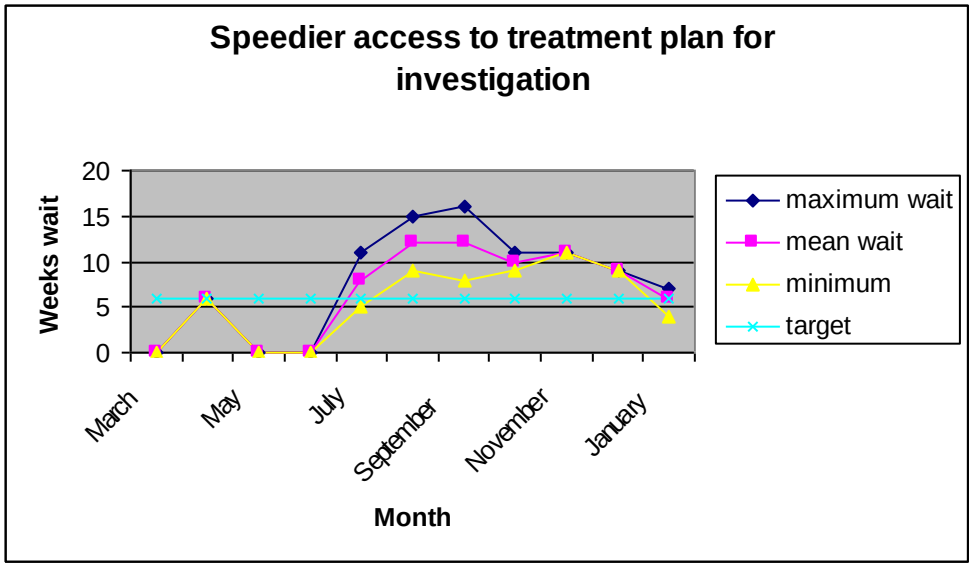
Speedier access to a management plan (patients that do not require further investigations).

The original target was that patients who did not need further investigations could be diagnosed and provided with a management plan within 2 weeks from GP referral to 1^{s} appointment. This was not a manageable target. The clinic started at the end of May and so those patients referred in March and April had been on the Scarborough waiting list. These patients were therefore transferred over to the new clinic in May. However there were not as many transfers from the Scarborough waiting list as expected.



The clinic went “live” to GP referrals in July and there was a rise in waiting times after annual leave was taken in August and September. It was also recognised in September that less follow up slots were needed and this meant that one additional slot was given to new patients, thus allowing some patients to “jump the queue.” However the mean waiting time from July onwards was between 4-8 weeks. (NB This graph can also be viewed as waiting time from referral to 1st appointment, excluding those patients that go on to have further investigations)

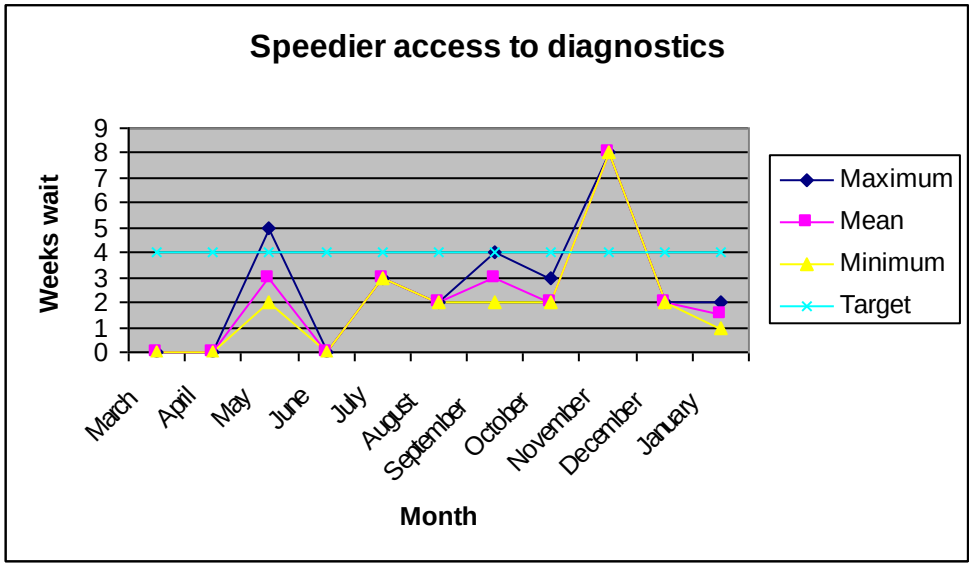
Speedier access to a management plan for patients that require further investigations



For patients needing further investigation the target for receiving a diagnosis and a management plan was 6 weeks from GP referral to 2nd appointment. This target was also unrealistic. However when this graph is looked at in combination with the diagnostic graph is it evident that the delay in the pathway was for the first appointment as the patient left the clinic with the date for the second appointment (within 6 weeks) and 84% (27/32) investigations were done within this timeframe.

Speedier access to diagnostic tests/reports

The project aimed to improve response times for specialist investigations and the target was that patients who needed a CT scan were given an appointment and reported on within 4 weeks.

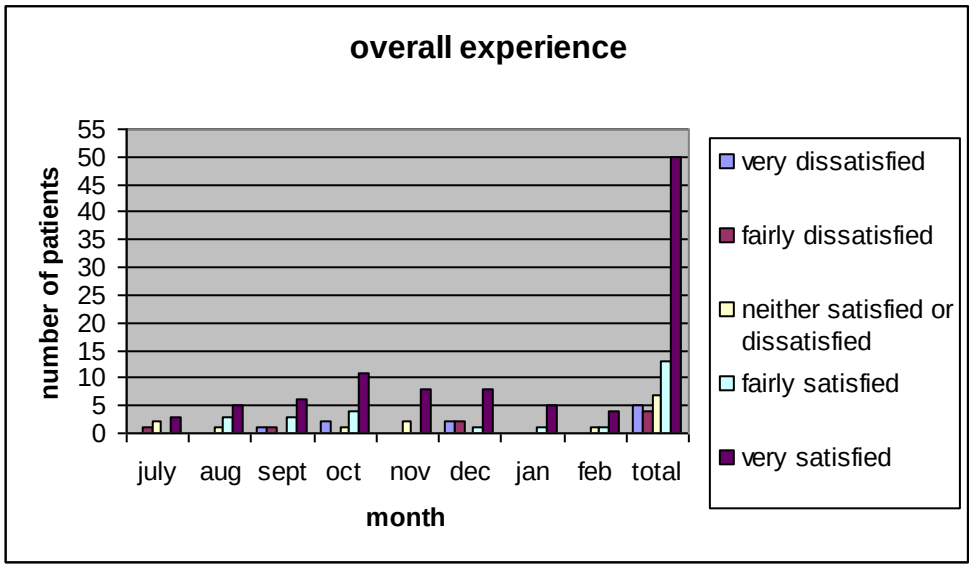


91% (20/22) of patients referred on for a CT scan were under the 4 week target. 1 patient waited 5 weeks and 1 patient waited 8 weeks.

Of the other investigations requested 100% (4) of all blood requests have been completed within the timeframe and 50% (4) of MRI scans were completed within the time frame. I patient waited 9 weeks for an MRI and 1 patient waited 15 weeks for an MRI. The patient referred for a Carotid Doppler was investigated within the time frame while the patient referred for a biopsy waited 10 weeks.

Patient Questionnaire
Patients were asked to complete a questionnaire on their clinic experience after they had been seen for their appointment. The questionnaires were given to patients after the clinic appointment in various ways including being given by a voluntary worker, being given by the specialist nurse or by being posted to their home address. All returns were anonymous and the results were posted back to the project manager for analysis. Questionnaires were first given to patients in July and then this continued for the remainder of the project up until February. A total of 79/150 returned = 53%. For a summary of the results please see appendix 9

Question 10 asked all things considered how satisfied were you with your overall experience at the clinic?



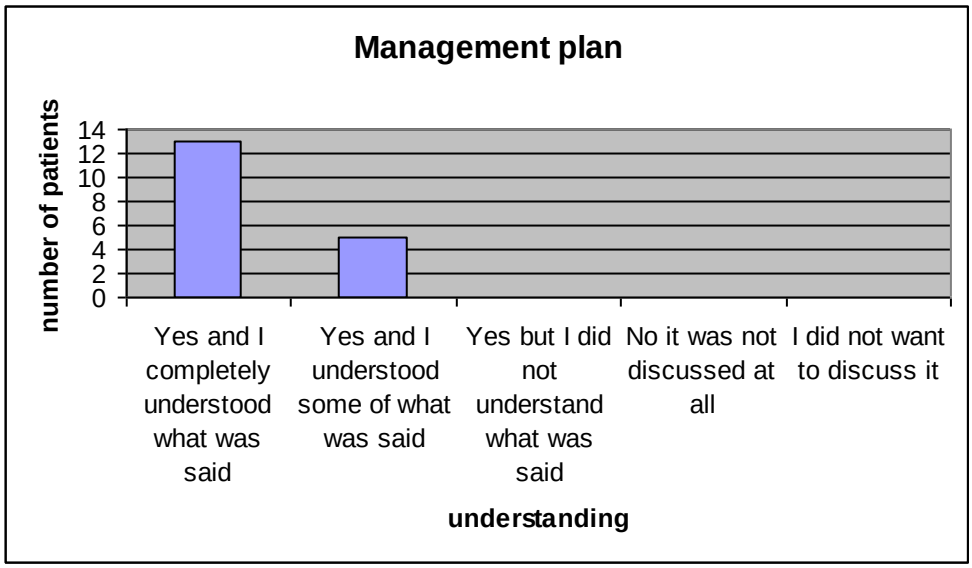
Of the patients who replied 80% (63) were either very satisfied, 63% (50), or fairly satisfied, 16% (13), with their overall experience at the clinic. 9% (7) patients expressed that they were neither satisfied nor dissatisfied and 11% (9) patients indicated that they were either fairly dissatisfied, 5% (4), or very dissatisfied, 6% (5).

Of those patients that were dissatisfied comments included feeing rushed in the appointment (particularly for follow up appointments) and a couple of patients expressed frustration in that they could not at the time identify whether the appointment would result in a solution to their headache symptoms. With the employment of the nurse specialist efforts were made to address the issues that the patients had highlighted. Indeed initial findings provided by the patients that returned questionnaires indicate that if a patient was also seen by the nurse overall satisfaction was better and the patients indicated that they have a greater understanding of their diagnosis and management plan.

Patients replies to Q10 when seen by both the GPwSI and Nurse Specialist

Of the 18 patients that returned questionnaires indicating that they were seen by both the GPwSI and Nurse Specialist 94% (17) were either very satisfied, 77% (14), or satisfied, 17% (3). 6% (1) was neither satisfied nor dissatisfied and 0% (0) were fairly dissatisfied or very dissatisfied.

Patient understanding of their management plan when seen by both the GPwSI and Nurse Specialist



Of the 18 patients that returned questionnaire indicating that they were seen by both the GPwSI and Nurse Specialist 72% (13) completely understood their management plan and 28% (5) understood some of what was said. No patients said that they did not understand their management, that their management was not discussed or they did not want to discuss it.

A wide range of comments from patients were also recorded and can be found in the summary of the questionnaire in appendix 9.

Additional resources have been developed by the specialist nurse and include

- Frequently asked questions – Tension type headache
- Frequently asked questions – Migraine
- Frequently asked questions – Cluster headache
- Frequently asked questions – Medication Overuse headache
- Medication overuse management plan
- Complementary therapies information sheet
- Lifestyle advice information sheet
- Pre clinic headache assessment diary
- Lifestyle packs – which includes leaflets regarding 5 a day, healthy walks scheme, stop smoking helpline

All these resources have been enthusiastically received by patients and can be found in appendix 10 -19.

GP management plans were also developed at the start of the project and although it is recognised that the Migraine and Chronic Daily Headache leaflets need further revision they have also been included in the appendix 20-22 for information. (Please note appendix 20 & 21are “publisher” documents and so are attached separately.)

5.4 Clinical outcome

Service benefits
From May- February progress and clinical findings in summary are:

- 161 new patients attended an appointment
- 28 Follow ups
- 28/161 = 17% follow up rate

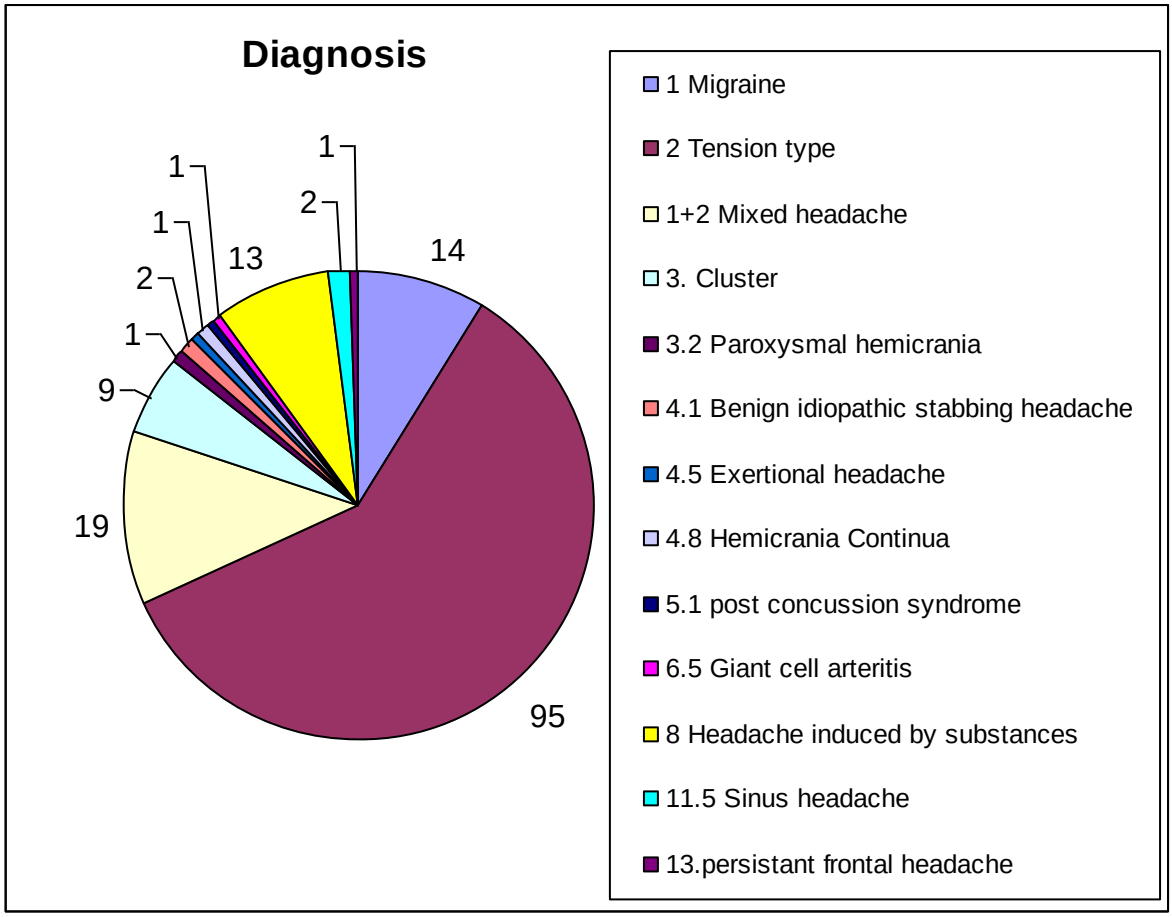
Number and type of Investigations requested

Investigation request	**Number of investigations**	**Percentage**
Bloods	4	13%
CT brain	22	68%
Biopsy	1	3%
MRI	4	13%
Carotid Doppler	1	3%
Total	32 investigations requested	100%

Of the 161 patients seen 17% (28) were sent for further investigation and followed up. A total of 32 investigations were requested, 24 patients had 1 investigation and 4 patients had 2 investigations.

To date only 1 patient has been referred onto another specialist with Giant Cell arteritis

The clinical finding have been summarised according to diagnosis and clasified according to the International Headache Society Classification Guidelines (1988)



(+1 patient currently not fully diagnosed with trigeminal autonomic cephalgia awaiting MRI scan in March)

The data therefore indicates that there is a need for further education of GPs in diagnosing and managing headache particularly of the tension type variety.

Of the main headache types that were diagnosed 59% (95/160) were diagnosed with tension type headache, 12% (19/160) presented with mixed headache and 9% (14/160) with migraine. 8% (13/160) were diagnosed with headache induced by substances and 6% (9/160) with cluster headache.

Patients followed up by the Nurse Specialist

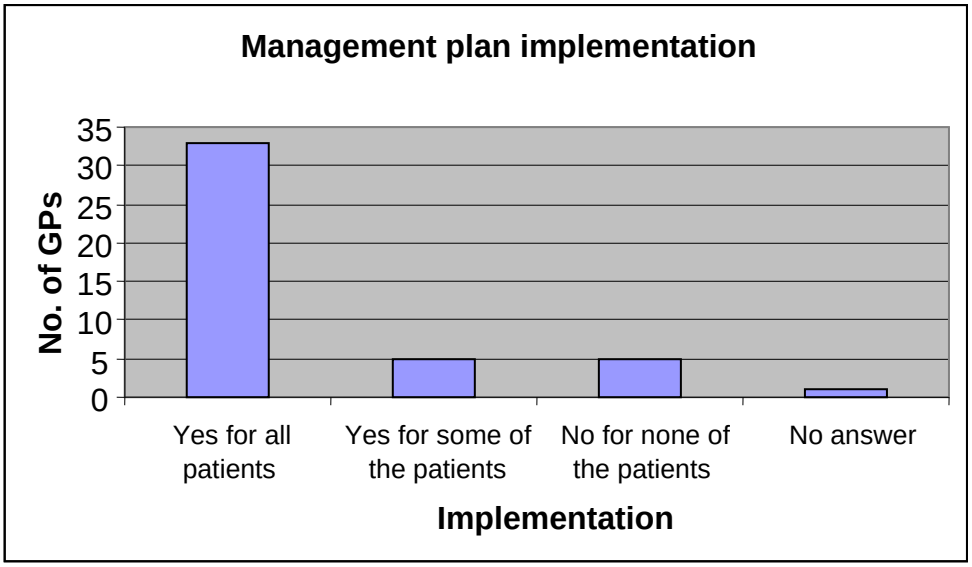
Type of headache	Number of patients	Number of times contacted by telephone
Cluster	2	1 patient x1 1 patient x1
Medication Overuse Headache	7	3 patients x4 1 patient x16 1 patient x7 2 patients x1 (hand over to practice nurse/GP as the pilot project ends)
Menstrual Migraine	2	1 patient x3 1 patient x1
Tension Type Headache	2	1 patient x1 1 patient x2
Hemicrania	1	1 patient x1
Total	**14**	

5.5 GP Experience/Opinion

All GPs in the SWRPCT and YWCPCT areas were asked to complete a questionnaire in September and January, which looked at referral patterns for patients with symptoms of headache, how satisfied they were with the service that they received and how confident they were in managing headache. A summary of the findings from the questionnaires can be seen in appendix 23 & 24.

Results from both questionnaires indicate that there has been a general increase in the overall satisfaction the GPs have in relation to the service that the patient has received and in particular they are more satisfied with the information they receive after the consultation. They are also more aware of the written information which has been received by the patient. The questionnaires do not however show that GPs confidence in managing headache has increased and it is recognised that further work could be done in this area.

In the second questionnaire which was specifically about the headache clinic the 44 GPs who had returned questionnaires were asked if they had implemented the management plan for the patients. 75% (33) had implemented them for all patients, 11% (5) had implemented them for some patients and 11% (5) had implemented them for none of the patients. 3% (1) GP did not answer the question.



When asked why the GPs had not implemented the management plan 5 gave no answer, 2 stated that the patient had not returned to the surgery after their outpatient appointments, 2 indicated that the patients headache had resolved by the time they returned to the surgery and 1 GP indicated that it was an inappropriate suggestion as the patient was intolerant of the suggested dose (in part).

Effort was made to address these issues as the Nurse Specialist followed up some patients by phone. If the patient had not had their management plan put in place further contact was made with the patient's GP. However it is recognised that in order to ensure that all management plans are implemented this telephone follow up would have to be done for all patients.

5.6 Finance and resource implications

The pilot project was originally worked out on the basis that the GPwSI would do 2.5 programmed activities per week to allow for development and clinic set up. Although this was acceptable for the set up period it was recognised that as only 1 clinic per week was being held this would need to be reduced to 1.5 PA per week for the clinic to be financially sustainable (for further details of GPwSI contract see appendix 25.)

Other alterations to the initial financial plan include a reduction in the number of CT scans needed. It was originally estimated that an additional 3 CT scans per week would be needed (over current service level agreement) but the number of requests has not been as high as expected and this was therefore reduced to an additional 1 per week

Finally although recommendation is made that the Nurse Specialist attends the Migraine Trust Diploma in headache the length of the pilot project made this impossible as the course was over a year and the nurse was initially employed on a 6 month secondment. Costs are not included for this as it is possible to obtain a bursary from the Migraine Trust.

Resource	WTE/notes	Set up	Ongoing
Staff			
Lead Clinician – GPwSI	0.25 reducing to 0.15 PA	23,803	15,121
Admin Support to Clinics – secretary (grade 4)	0.10	1,829	1,829
Admin Support to Clinics – reception (grade 2)	0.08	1,039	1,039
Nurse support to clinic – (Grade A)	0.11	1,699	1,699
Specialist Nurse (grade G)	0.40	19,088	19,088
Venue/ equipment			
2 clinic rooms per venue, 1 afternoon per week Office space 2 days for Nurse		- -	No costs available No costs available
Computer for nurse		1,300	-
Phone for nurse		25	-
Answer phone for nurse		25	-
Stationary and printing for management plans/patient information/proformas		1,500	-
Investigations			
Additional Diagnostic Costs (CT Scans)	Originally +3 per week reduced to +1 per week	2,500	833
Training/Consultant support			
Training/CPD GPwSI		No costs available	500
Consultant support		-	-
Nurse training – Migraine trust diploma in headache and Migraine		£680* (bursary available)	-
Total		**52,838**	**40,109**

Other resource requirements:

In order to make the change happen tasks to be done include:

- Time to organise job descriptions and recruit GPwSI and nurse specialist
- Time to work with Consultant/GPwSI/GPs to develop and agree referral guidelines and protocols
- Consultant time to train GPwSI (not applicable in this project as GPwSI had already had considerable experience as a clinical assistant in Neurology)
- Consultant time to train nurse specialist
- Managerial/clinical time to plan and manage the project
- Time to work with radiology to agree protocol, booking and reporting process of investigations

- Time to collect data in order to plan and review the service change.
- Time to develop and produce management plans/patient information/patient diaries

GPwSI versus Secondary care cost analysis

A forecast analysis of the headache clinic compared to an outpatient appointment being provided in secondary care show the following costs.

The headache clinic activity for 10 months from the last week of May until the end of March was 161 new patients seen for an appointment and 28 follow up patients seen for an appointment (not including telephone follow ups by nurse).

161/10 = 16 per month new = 192 per annum
192 x tariff cost £197 (provided by SWRPCT) = 37,824
28/10 = 2.8 per months fu = 33 per annum
33 x tariff cost £123 (provided by SWRPCT) = 4,059

Total = 41,833
Ongoing costs (as provided above) = 40,109

The headache clinic would therefore operate at 96% of the cost of an outpatient appointment based on these figures. It must however be recognised that the clinic was not always working to capacity especially as the month of June and month of March had reduced capacity due to set up and closing down procedures. If the clinic was working to capacity as given in previous tables this percentage would therefore reduce further.

6 Risks of not continuing the service

The risks of not continuing the service include:

- An increase in referrals to Neurology for symptoms of headache over and above the original figure as some unmet need was discovered by the project.
- An increase in waiting times due to increased numbers of referrals
- Loss of skills developed by the GPwSI and Nurse Specialist
- Loss of opportunities to further develop Neurology services
- Loss of opportunities to further develop services closer to the patient
- Loss of GP support through constant referral route changes
- Loss of patient support as headache patients may see the discontinuation of the service as a lack of concern for headache symptoms.

7. Issues preventing the service from continuing

Several issues which remain unresolved at the end of the pilot stage have prevented the service from being continued. These include:

- A lack of agreement with clinical staff whether GPwSIs should be on an incremental pay scale
- A lack of agreement on where a GPwSI clinic should be held and the availability of such premises. I.e. in the secondary care outpatients of a district general hospital or in primary care outpatients of a community hospital.

In addition to this the pilot project has been run at a time when PCTs are going through a period of financial restrictions and although several different models of service delivery have been explored it has not been possible to secure further funding at this time.

8 Learning

Learning from the project includes:

- The line management, accountability and provision of specialist support for all medical staff needs to be made clear when staff are spread over several geographical sites.
- It is possible to move secondary care services out into the community using the skills of either a GPwSI or Specialist Nurse
- Clear communication channels are needed between all organisations and individuals involved.
- Where possible resources or contingency plans need to be made available for those times when specialist staff are unavailable
- Clear education and training guidelines for new posts need to be developed before new staff are employed.
- As much detail as possible should be given in new contracts which deal with new roles before staff are employed.
- Long term project sustainability and systems should be considered and developed before embarking on short term trials
- Achievable waiting time targets should be chosen

9 Conclusions

In conclusion as the clinic has only been a short term trial it has not been possible to fully evaluate the impact which has been made clinically on the patient's management and it is recommended that further work is needed in this area. In addition to this the project has highlighted the importance of providing greater education to GPs.

The pilot GPwSI headache service has however provided evidence that the diagnosis and management of headache symptoms can be provided by specialist primary care practitioners. This can help to reduce the waiting times for both new appointments and follow up appointments and reduces the numbers of patients with headache symptoms that are referred to secondary care. In general the findings of this pilot project indicate that both GPs and patients have expressed satisfaction with the clinic and there has been recognition that the nurse specialist role enables a more holistic patient experience to be provided and increase the effectiveness of the communication between the different health care professionals and patient. The project has also demonstrated the possibilities and opportunities that further development of the roles of the GPwSI and Nurse Specialist would provide in modernising neurology services.

Appendices

Appendix 1

Staff & equipment needed

For the GPwSI service in headache to be operational the following needs to be in place:

Staffing
Clinic/operational staff

- GPwSI
- Nurse Specialist
- Medical Secretary
- Reception/outpatient staff
- Health care assistant

Clinical network

- Clinical mentor for both the GPwSI and Nurse Specialist
- Secondary care specialist

Clinic management
Management by nurse specialist or outpatient department

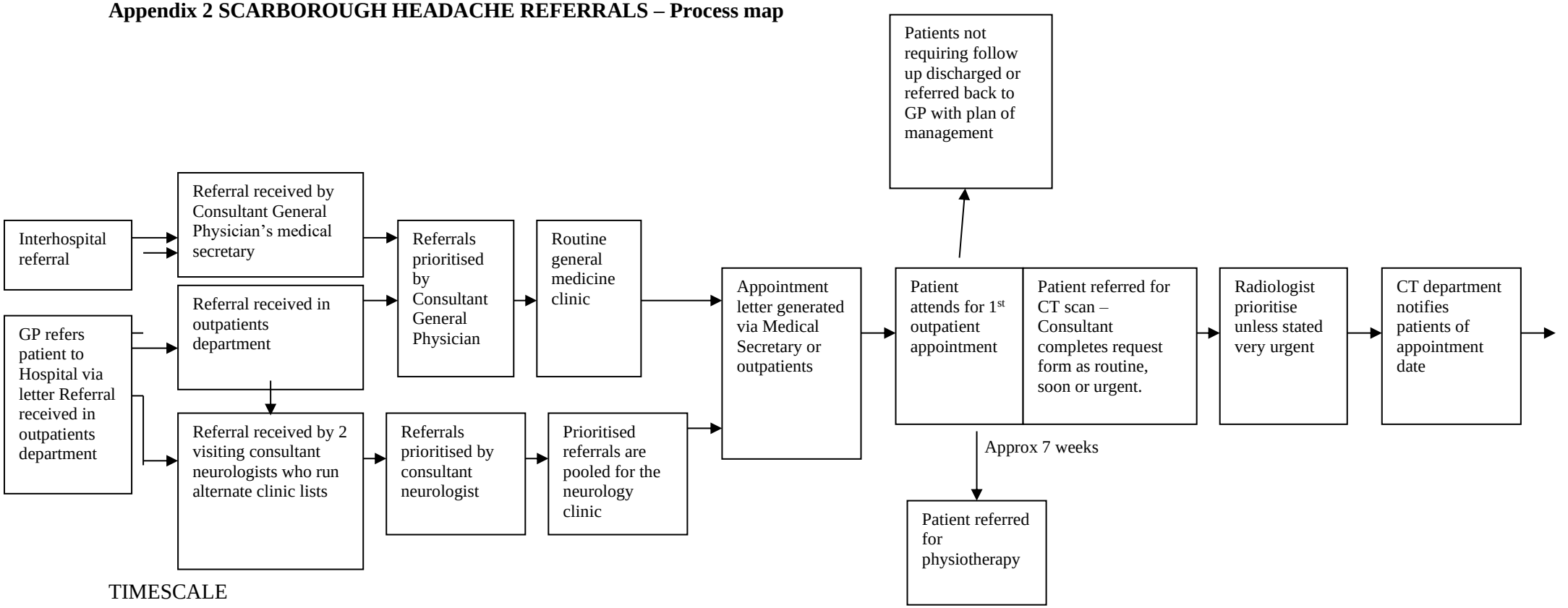
Kit
For the clinic to function the following equipment is needed:

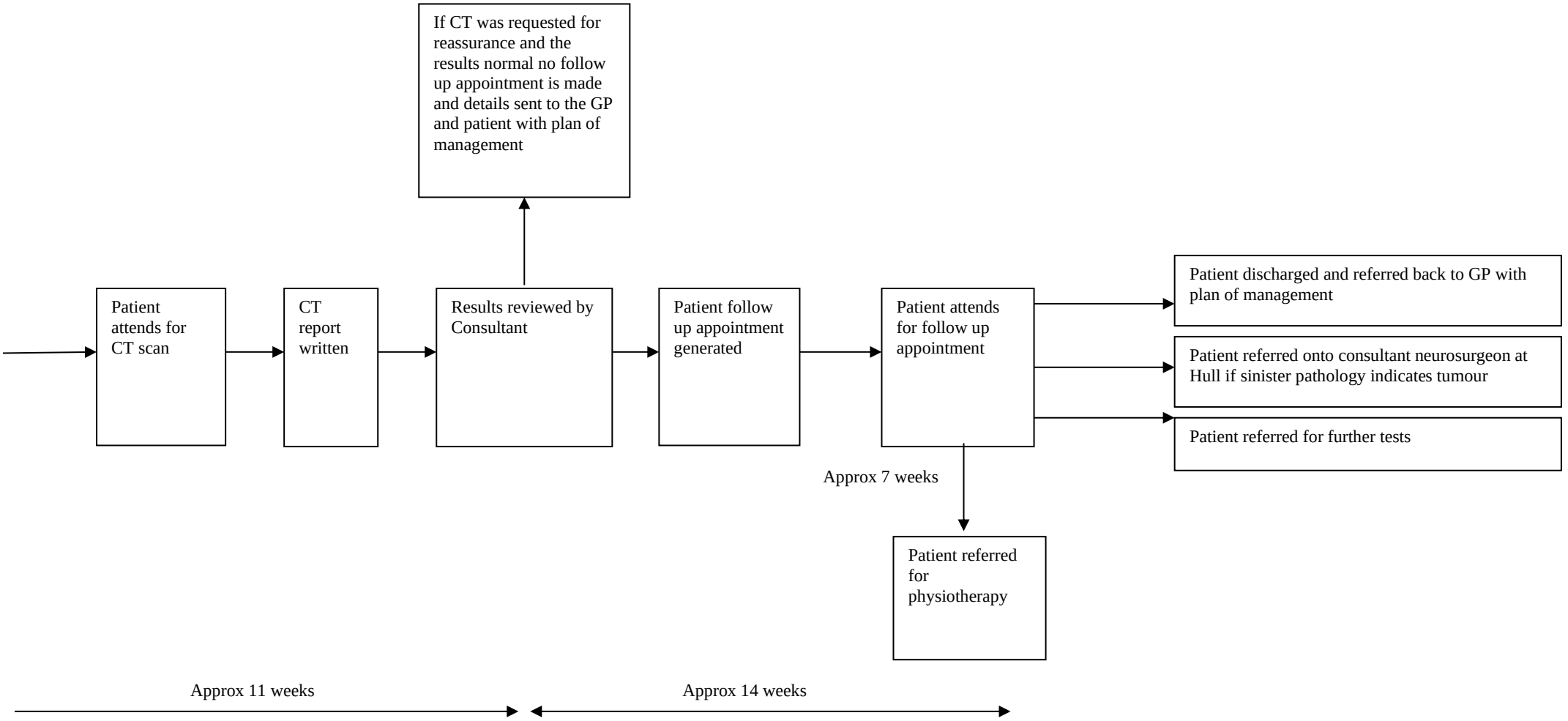
- Fax machine (reception)
- Phone (nurse office)
- Computer (nurse office)

Estate requirements include:

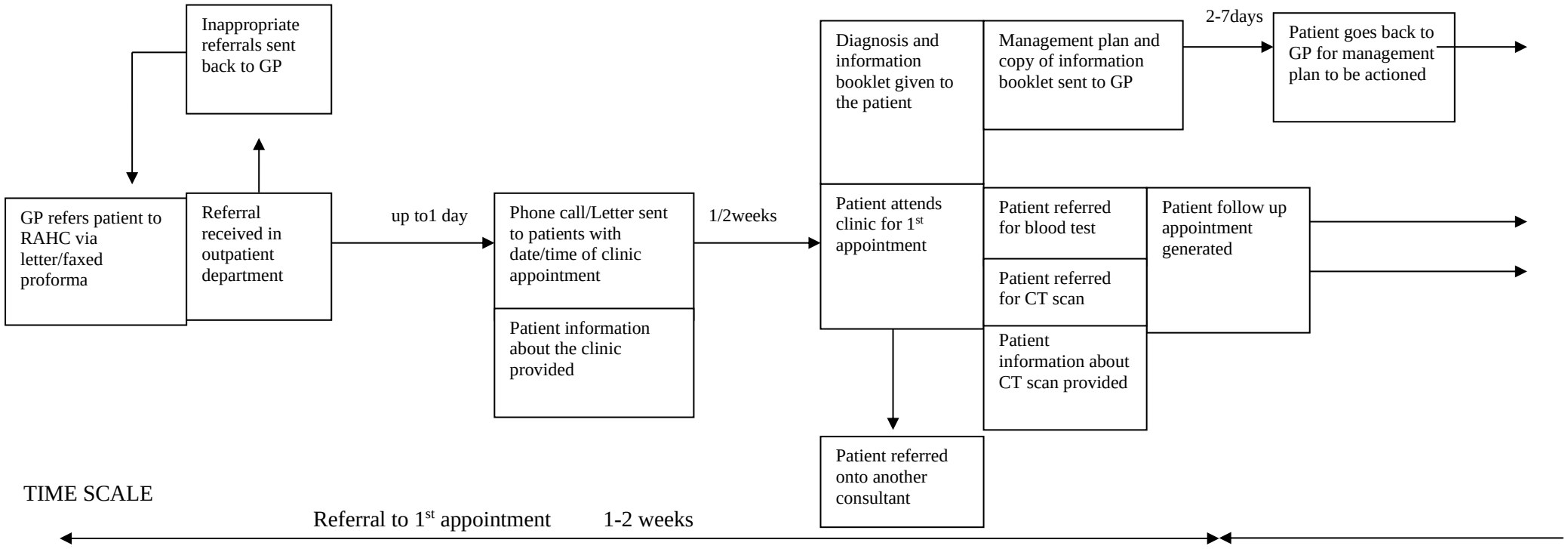
- 2 clinic rooms on one afternoon per week
- an office for the nurse specialist 2 days per week

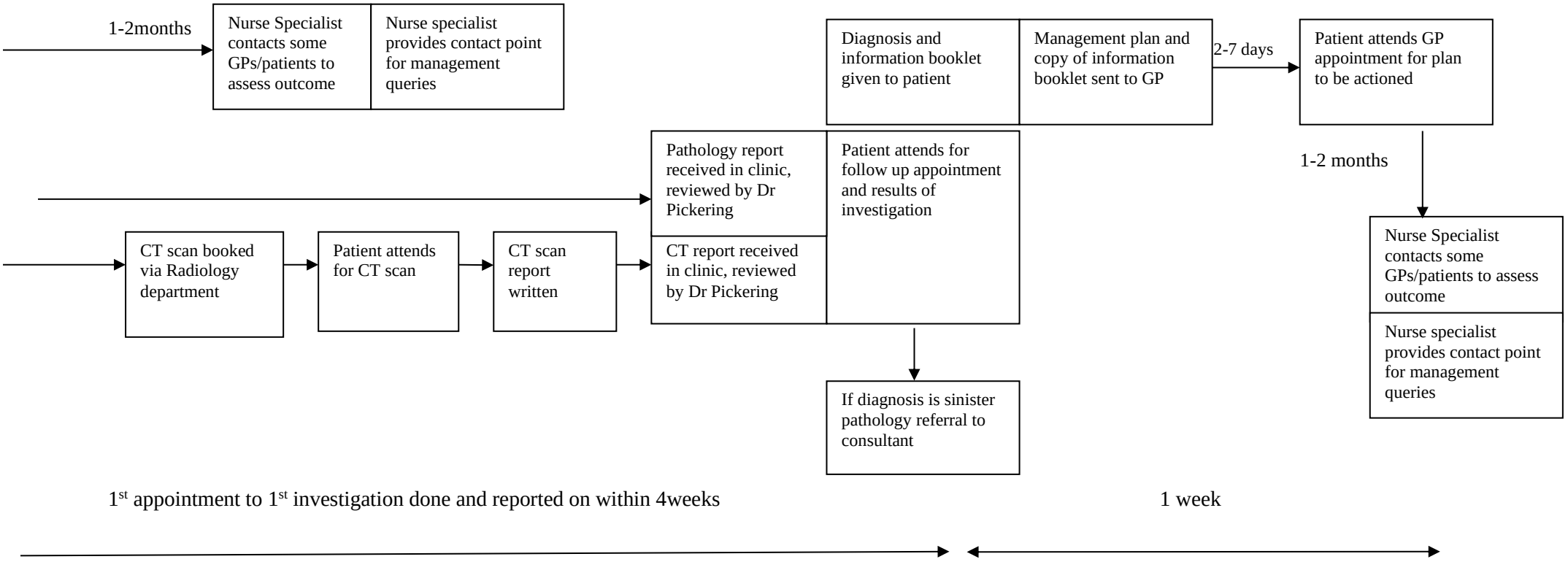
Appendix 2 SCARBOROUGH HEADACHE REFERRALS – Process map




If CT was requested for reassurance and the results normal no follow up appointment is made and details sent to the GP and patient with plan of management
Patient attends for CT scan
CT report written
Results reviewed by Consultant
Patient follow up appointment generated
Patient attends for follow up appointment
Patient discharged and referred back to GP with plan of management
Patient referred onto consultant neurosurgeon at Hull if sinister pathology indicates tumour
Patient referred for further tests
Approx 7 weeks
Patient referred for physiotherapy
Approx 11 weeks
Approx 14 weeks

Appendix 3 RAPID ACCESS HEADACHE ASSESSMENT CLINIC




1-2months
Nurse Specialist contacts some GPs/patients to assess outcome
Nurse specialist provides contact point for management queries
Diagnosis and information booklet given to patient
Management plan and copy of information booklet sent to GP
2-7 days
Patient attends GP appointment for plan to be actioned
1-2 months
Nurse Specialist contacts some GPs/patients to assess outcome
Nurse specialist provides contact point for management queries
Pathology report received in clinic, reviewed by Dr Pickering
Patient attends for follow up appointment and results of investigation
CT scan booked via Radiology department
Patient attends for CT scan
CT scan report written
CT report received in clinic, reviewed by Dr Pickering
If diagnosis is sinister pathology referral to consultant
1st appointment to 1st investigation done and reported on within 4weeks
1 week

ACTIVITY	RESPO	MAY		JUNE				JULY				AUG				SEPT				OCT				NOV				DEC				JAN				FEB			
		3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
1.1 Referral guidelines and Proforma developed and distributed	GPwSI + PM																																						
2.1/2 Booking and reporting process of CT scans agreed	PM + Planning																																						
2.3 Booking and reporting of other investigations agreed i.e. blood test	PM + planning																																						
3.1/2 Management plan on each condition developed	GPwSI + PM																																						
4.1/2 Letter advertising clinic developed and distributed	GPwSI + PM																																						
4.1/2 Publicity organised	PM + corp services																																						
4.1/2/4 Full booking procedures in place for clinic	PM + Planning																																						
5.1 Training/CPD opportunities identified for GPwSI	GPwSI/Board																																						
5.2 Job description and person specification developed for Nurse Specialist	PM + Planning																																						
5.2 Job advertised and person recruited	PM + Planning																																						
5.2 Training opportunities for nurse specialist identified	Clinical leads + Nurse + PM																																						
6.1 patient information on condition/additional support developed	GPwSI + Nurse + PM																																						
6.1 Support group/links with expert patient programme developed	Nurse + PM																																						
7.1 Educational sessions run by GPwSI for GPs	GPwSI + PM																																						
8.1 Business case developed and submitted to LDP	PM + Board																																						
Additional																																							
Data collection organised	PM																																						
Staff questionnaire written/distributed/analysed	PM + planning																																						
Patient questionnaire written/distributed/analysed	PM + planning																																						
Focus group organised/held/transcribed/analysed	PM + planning																																						
Operational policy for clinic developed	PM + planning																																						
admin support to clinic organised	Planning																																						
nurse support to clinic organised	Planning																																						
Project evaluation written	PM + planning/board																																						

Appendix 5
Clinical parameters
(Reference DoH guidelines for the appointment of GPwSI Headache)

The types of conditions that can be diagnosed and treated by the GPwSI are:

- Migraine including: patients with contraindications to medications; medication-related side effects; co-morbidities and those at risk, e.g. certain women and those overusing symptomatic medications
- Patients with chronic headaches: Chronic Daily headache (CDH) and Medication Overuse/misuse Headache (MOH)
- Patients with short-lasting headaches: Cluster Headache and short, sharp headaches
- Headaches associated with old age: trigeminal neuralgia, post-herpetic neuralgia and temperomandibular dysfunction.
- Patients with refractory “sinus” headache

It is recommended that the following patients are referred onto a neurologist/other specialist consultant

- Patients with suspected sinister headache
- Patient’s refractory to repeated treatments given by GPwSI
- Patients with rare headache subtypes
- Patients who have previously been extensively investigated by secondary care
- Children (persons under the age of 16 years old)

Appendix 6
Referral guidelines

Rapid Access Headache Assessment Clinic

Referral Guidelines

Please refer:

Patients with headache of new onset or chronic duration which either presents a difficulty in diagnosis or treatment to primary care

Please don't refer:

Patients whose symptoms are longstanding and unchanged or who have previously been extensively investigated by secondary care

Children (persons under the age of 16 years old)

Appendix 7

Rapid Access Headache Clinic Referral Proforma
Bridlington District Hospital
Fax 01262 423032

Page 1/2

Patient details
NHS Number (essential)
Patient Name
Patient Address & postcode
Telephone Number (essential) Mobile:
Date of Birth
Referring GP, Surgery Address and Tel Number
Is the patient able to attend an appointment at short notice? (within a week) Y/N

Symptom/referral details	
Date of onset of symptoms	Frequency of symptoms
History of trauma Y/N If Y details	
Family History of Migraine Y/N If Y details	
Site of pain	Type of pain e.g. pressure, sharp etc
Exacerbated by e.g. lying down, head movement etc	Ameliorated by e.g. lying down, sleep etc
Analgesia previously tried	Preventors previously tried e.g. amytriptyline
Clinical findings normal/abnormal If abnormal details	
BP	

Previous investigations – date and findings (Please enclose copies where appropriate) CT scan brain normal/abnormal If abnormal details Other	
Past history	Current medication
Additional Comments	

For Clinic use only	
Date Referral received	Date 1st appointment offered
Date Seen	
Referred CT Scan Y/N Results Other Investigation Y/N	
Date Follow up	Diagnosis
Management plan given Y/N	Discharge Date

Appendix 8
GP Referral geographical distribution

Scarborough, Whitby & Ryedale GP Practice	Number of new patients referred
Practice 1 Scarborough	0
Practice 2 Scarborough	9
Practice 3 Newby, Scarborough	4
Practice 4 Newby, Scarborough	0
Practice 5 Scarborough	5
Practice 6 Scarborough	6
Practice 7 Scarborough	13
Practice 8 Scarborough	15
Practice 9 Scarborough	10
Practice 10 Scarborough	1
Practice 11 Scarborough	6
Practice 12 Scarborough	2
Practice 13 Hunmanby	5
Practice 14 Filey	2
Practice 15 Sherburn	1
Practice 16 Norton	7
Practice 17 Pickering	4
Practice 18 Helmsley	0
Practice 19 Kirkbymoorside	1
Practice 20 Ampleforth	1
Practice 21 Terrington	0
Practice 22 Sleights	2
Practice 23 Whitby	0
Practice 24 Whitby	0
Practice 25 Whitby	0
Practice 26 Saltburn	0
Practice 27 Whitby	1
Total	**95**

Yorkshire Wolds and Coast GP practice	Number of new patients referred
Practice 28 Hornsea	3
Practice 29 Bridlington	13
Practice 30 Market Weighton	0
Practice 31 Bridlington	5
Practice 32 Withernsea	5
Practice 33 Beeford	4
Practice 34 Pocklington	1
Practice 35 Driffield	5
Practice 36 Holme on Spalding Moor	0
Practice 37 Hedon	1
Practice 38 Bridlington	5
Practice 39 Hedon	5
Practice 40 Bridlington	5
Practice 41 Bridlington	6
Practice 42 Driffield	6
Total	**64**

+ 2 referrals from hospital consultants.

Appendix 9

Patient questionnaire – Clinic experience
A Summary of the analysis of returns
July 2004-end of February 2005

Patients were asked to complete a questionnaire after they had been seen in clinic. The questionnaires were given to patients after the clinic appointment in various ways including being given by a voluntary worker, being given by the specialist nurse or by being posted to their home address. All returns were anonymous and the results were posted back to the project manager for analysis. 79 patients returned questionnaires out of a total of 150 distributed = 53% return rate.

Nurse input - Of the returns received from November to February 18 were marked to show that they had also been seen by the nurse specialist. The findings indicate that general satisfaction increased if the patient was also seen by the nurse specialist. Results for those patients who were also seen by the nurse are shown at the end of this summary.

Do you feel that the time the doctor spent with you on this occasion was too long, too short or about right?
Of the 79 returns 96% (76) were new appointments and 4% (3) were new appointments. No patient felt that there appointment was too long and the majority 85% (67) indicated that the appointment length was about right. 14% (11) indicated that the appointment was too short and this included all 3 patients who returned questionnaires after a follow up appointment all 3 indicated that they thought it was too short. 1% (1) did not answer

Thinking about your consultation how do you rate the following?
a) The technical skills (competence, carefulness, thoroughness) of the specialist you saw?
70% (55) of patients indicated that the felt the technical skills of the specialist they saw was either very good 37% (29) or good 33% (26). Of the remaining 25% (20) were satisfied with the technical skills with 4% (3) indicating that they felt they were poor and 2% (1) indicating that they were very poor.

b) The personal manner (courtesy, respect, sensitivity and friendliness)?
76% (60) of patients indicated that the personal manner of the specialist was either very good 48% (38) or good 28% (22). An additional 18% (14) felt that the specialist's personal manner was satisfactory while 6% (5) patients indicated it was poor. No patient indicated that it was very poor.

c) How well the doctor listened to what you had to say
70% (55) indicated that how well the doctor listened to what they had to say was very good 42% (33) or good 28% (22) An additional 22% (17) felt that it was satisfactory while 4% (3) patient felt it was poor and 3% (2) very poor.

Was you diagnosis explained to you by the doctor/nurse?
When asked about the explanation of their diagnosis the 78% (62) of patients who returned questionnaires felt that it had been explained and they completely understood what had been said while 18% (14) others felt it had been explained and they had understood some of what had been said. 1% (1)

said yes but they did not understand any of what was said, 1% (1) patient indicated that it had not been discussed at all and 1% (1) did not answer

Was your management plan explained to you by the doctor/nurse?
When asked if the management plan had been explained to them the 72% (57) of patient had said it had been explained but of this 56% (44) completely understood 14% (11) understood some and 3% (2) did not understand However 25% (20) patients said it was not discussed and 1% (1) patient indicated they did not want to discuss it and 1% (1) gave no answer

Provision and quality of written information
Written information did not start to be given out until November and so only 33% (26) patients received any. 100% (18) patients said that the information was easy to read. 94% (17) patients said it was easy to understand and 6% (1) gave no answer. 94% (17) patients indicated that it was of benefit and 6% (1) gave no answer. 94% (17) patients said it was given at the right time and 6% (1) gave no answer.

All things considered how satisfied were you with your overall experience at the clinic?
Of the patients who replied 80% (63) were either very satisfied 63% (50) or fairly satisfied 16% (13) with their overall experience at the clinic. 9% (7) patients expressed that they were neither satisfied nor dissatisfied and 11% (9) patients indicated that they were either fairly dissatisfied 5% (4) or very dissatisfied 6% (5)

Nurse input
(These responses are from patients who were also seen by the nurse)

Do you feel that the time the doctor spent with you on this occasion was too long, too short or about right?
All 18 patients indicated that they attended new appointments and 94% (17) thought that the appointment length was about right. 6% (1) indicated that it was too short. 0 indicated that it was too long.

Thinking about your consultation how do you rate the following?
a) The technical skills (competence, carefulness, thoroughness) of the specialist you saw?
Of the 18 patients who returned questionnaires 83% (15) indicated that the technical skills were either very good 33% (6) or good 50% (9). 17% (3) indicated that they were satisfactory. 0% (0) patients indicated that they were poor or very poor

b) The personal manner (courtesy, respect, sensitivity and friendliness)?
Of the 18 patients 94% (17) indicated that the personal manner was either very good 61% (11) or 33% (6) good. 6% (1) indicated the personal manner was satisfactory. 0 indicated that it was poor or very poor.

c) How well the doctor listened to what you had to say
Of the 18 patients who returned questionnaires 83% (15) indicated that the listening skills were either very good 33% (6) or good 50% (9). 17% (3) indicated that they were satisfactory. 0% (0) patients indicated that they were poor or very poor

Was you diagnosis explained to you by the doctor/nurse?
Of the 18 77% (14) said that their diagnosis was explained and they completely understood what was said. 17% (3) said that their diagnosis was understood some of what was said. 6% (I) patient did not give an answer.

Was your management plan explained to you by the doctor/nurse?
Of the 18 patients 72% (13) completely understood their management plan and 28% (5) understood some of what was said. No patients said that they did not understand, it was not discussed or they did not want to discuss it.

All things considered how satisfied were you with your overall experience at the clinic?
Of the 18 94% (17) were either very satisfied 77% (14) or satisfied 17% (3), 6% (1) was neither satisfied nor dissatisfied. 0% (0) were fairly dissatisfied or very dissatisfied.

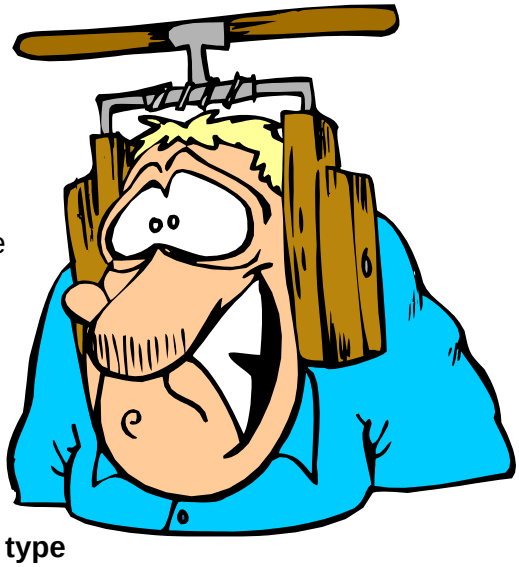
In general patients who were seen by both GPwSI and the Nurse Specialist appeared to be more satisfied with the overall clinic experience and the patients were more likely to indicate that they understood their diagnosis and management plan.

A few of the additional comments that were provided by patients include:

- If my own GP had told me what I was told at the clinic it would have saved a lot of time and worry
- The information given was very helpful in giving ideas to assist alleviating the problem
- The consultant was rather abrupt. Very little guidance on managing pain on discharge
- No comments to make at all other than to say how impressed my wife and I were with the efficient way my consultation was handled and the obvious professionalism of those involved
- The session went too quickly. The Doctor in general was asking the questions too fast, and not giving (me) the patient long enough to explain the situation. However overall I was pleased with the service
- I was more than pleased with my consultation I was most impressed by the fact that I was not talked down to I did not feel rushed I was given a range of treatments that could be used and I could chose what suited best. I was not dictated to and most importantly I felt listened to, thank you.
- It was so good to have someone listen and understand how bad the headaches are and how they rule my life. I feel that after all these years I will now get somewhere
- The experience was rushed but overall it was very helpful in the advice received

Appendix 10

Frequently asked questions Tension Type Headache



What is a tension type headache?

A tension type headache is caused by muscles in the head and neck tightening up and squeezing all the structures beneath i.e. the skull, nerves, blood vessels. This causes pain. We call this headache "benign" because it does not indicate a serious underlying cause. It can however be very painful and affect your daily life. It can be classified as chronic or episodic.

What is the difference between a chronic tension type headache and an episodic tension type headache?

Chronic means the headache is present for more than 15 days per month. Episodic means the headache is present less than 15 days per month.

What are the symptoms of tension type headache?

Tension headaches usually affect both sides of the head and are pressing or tightening in nature. There may be mild dislike of light or sound but this headache is not usually accompanied by nausea. It may be difficult to continue with daily activities but will not stop it completely. Chronic tension type headache becomes more continuous in nature and it is not uncommon to experience some nausea with this type of headache. Scalp tenderness, neck pain and back stiffness are often associated features. These however are generalisations, everyone's headache will be specific to them and so will the symptoms they experience.

What causes tension type headache?

Headaches can be triggered by a variety of causes:

- Stress - physical or psychological (related to stresses at home, work or to life events)
- Poor sleep, anxiety and depression
- Injury and trauma to the head and neck
- Poor posture – due to driving, use of computers, reading a lot

Sometimes we are not aware of feeling "stressed" or "tense" but the activities we do can create tension in our neck, head and shoulders. Over time this can lead to this type of headache.

How is a tension headache diagnosed?

There are no specific tests to diagnose tension type headache. Brain scans and blood tests can only exclude the possibilities of other causes not diagnose tension type headache. Therefore tests are usually not required and are often unhelpful when there are no other features with the headache. The most effective method of diagnosing any headache is to spend time taking a clear and detailed history and this will take up most of the consultation when in a headache clinic.

How is this type of headache treated?

This headache can be treated with medication but it is also important to consider whether any lifestyle issues are contributing to the development of headaches. Things such as water & caffeine intake, posture, stress levels are just some of the things that contribute to this headache type. Lifestyle issues will be discussed with you at your appointment. There are therefore three approaches to treating this type of headache:

a) Lifestyle assessment
b) Acute medication – this is medication for use at the time of having a headache e.g. aspirin or paracetamol or ibuprofen or a combination of paracetamol and ibuprofen.
c) Preventer medication – this is taken every day to try and prevent headaches occurring. Two main types of medication are used; anti-depressants e.g. amitriptyline and anti-epileptics e.g. sodium valproate.

What is preventer medication?
Many of the preventions were originally used as anti-depressants or anti-epileptic drugs but have been found to be very good at controlling pain and particularly useful in the treatment of headaches. Preventers are taken at the same time every day regardless of whether a headache is present. There are two main groups of preventative medication; anti-depressants e.g. amitriptyline and anti-epileptic medications e.g. sodium valproate. Amitriptyline is a commonly used drug for the treatment of headaches. It is prescribed at a very low dose and at this dose does not have an antidepressant effect. It has a muscle relaxant effect which is effective in the treatment of headaches. You will be prescribed amitriptyline at a dose of 10-75mg (possibly up to 150mg). This treatment will be continued for a minimum of 3 months and possibly up to 6 months.

What are the possible side effects of amitriptyline?

Dry mouth, drowsiness, blurred vision, nausea, constipation, difficulty urinating. It might be possible to decrease the dose to reduce side effects or to change to a different medication.

How long do I take my preventer medication e.g. amitriptyline?

You will take these until you are headache free. Once you have been headache free for 3 months then the dose will be decreased gradually until it is stopped completely. If you are still exposed to factors causing the headache e.g. stress, then medication will continue until it has passed.

What acute medication should I take to treat a tension type headache?

You could use any **one** of the following types of medication
- Aspirin 300 – 900mg every 4–6 hours
- Paracetamol 500g – 1g every 4-6 hours (up to maximum of 4g daily)
- Ibuprofen 400-600mg when needed
- Diclofenac 50mg when needed

Or you might use a **combination** of medication instead:
- Paracetamol 500g -1g every 4-6 hours (up to maximum of 4g daily) with ibuprofen 400-600mg or with diclofenac 50mg

Why is it necessary to discuss lifestyle issues when the problem I have is headache?

There are aspects of your lifestyle that can contribute to your headaches e.g. inadequate water intake, high stress levels, bad posture, lack of exercise etc. There are also other means of managing headache symptoms other than taking medication. It is important to use these wherever possible and not to become dependant on medication.

What other ways are there of managing a headache without using medication?

- Relaxation techniques
- Warm bath
- Aromatherapy oils
- Wheat bags
- Alternative therapies e.g. massage, reflexology, Bowen technique

Why should I avoid caffeine?

Caffeine causes headaches in several ways. It is believed to have a direct effect on tension type headache and migraine in addition to its dehydrating properties. Caffeine is found in tea, coffee and fizzy drinks such as coca cola.

How can I improve my headache symptoms?

- Set realistic time scales – your headache symptoms did not happen over night and they will not go away overnight
- Get support from those around you – making people aware of how you have been suffering helps them to understand you need more help and support
- Do not take analgesia regularly, try to avoid taking it more than 2 days a week, you can make your headache worse not better
- Remember to take your preventer medication every day. It is prescribed to help reduce the frequency of your headaches but it can take 2-3 months to be effective. It might take some time to get used to. See your GP if you experience any side effects, these should settle but if they become unacceptable it is possible to try another type.
- Do not worry if you are prescribed an anti-epileptic or anti-depressant drug to treat your headache. These are effective drugs for controlling pain and have been taken safely by many people with all types of pain including headache pain.
- Simple painkillers such as paracetamol, aspirin and brufen are usually very effective. Try to take them early in an attack before the pain becomes severe. They are more likely to be effective.
- Don't forget the lifestyle issues which contribute to this type of headache – keep vigilant about your water/caffeine intake, exercise levels, quality of sleep etc.
- Do go back to your GP if you are worried or contact your headache nurse.

Reference/with thanks to the Headache Clinic Team, Dept of Neurosciences, York District Hospital & Julie Edwards, City Hospital Birmingham

Appendix 11

Frequently asked questions Migraine

What is Migraine?

Migraine is a headache disorder that affects 12-15% of the population. It affects people of all ages but is most common in the 20-50 age groups. Around 2/3 of sufferers are women. There are two main types of migraine; migraine without aura and migraine with aura.

What is migraine without aura?

Previously known as common migraine this is the most common form of migraine (85% of sufferers). The pain of this type of migraine can be intense, pulsating and often occurs on one side of the head only. Movement can make it worse and generally sufferers want to keep still and quiet in a dark room. There can be an increased sensitivity to light, sound and strong smells. Sufferers may also experience nausea, vomiting or diarrhoea.

What is migraine with aura?

Previously known as classic migraine this is a less common form of migraine (15% of sufferers). The symptoms are similar to migraine without aura but the difference is that the sufferer experiences some neurological disturbances prior to the commencement of the headache. These disturbances occur 15 minutes to an hour before the headache and the potential symptoms are described below. Some people only experience the aura without going on to develop the headache or the headache can be mild.

What are the symptoms of migraine?

There are said to be five stages of a migraine. Not everyone will experience all of the following features. Every individual's symptoms are unique to them.

Prodrome: These are symptoms that occur up to 24 hours before the headache starts and act as a warning of the impending attack. It is possible at this stage to feel mood changes such as irritability, depression, elation or a feeling of well being. It is possible to feel drowsy, fatigued, to yawn or to be excited. There can be changes to sensory perception including a dislike of light, sound and strong smells. Approximately 30% of people can identify some of these features before their headache starts and may be able to avoid the headache developing.

Aura: This produces a variety of visual and sensory disturbances before or into the headache stage. Visual disturbances: blind spots, flashing lights, zig zag shimmering lines or areas of the vision may be missing and replaced by a black area. Other aura symptoms include dizziness, vertigo, pins and needles in the hand, arm or face. Difficulty with speech, balance and moving limbs can also occur but is generally less common. These experiences can be extremely frightening and disturbing but are usually harmless and cause no damage to the brain.

Headache: The headache stage is usually the most significant feature of migraine. It is generally described as throbbing, may be one sided and moderate to severe in intensity to the extent that it interferes with your ability to function normally. During the headache phase people commonly report a dislike of light, sound or strong smells and may be reluctant to eat or drink due to nausea, vomiting, abdominal pains or diarrhoea.

Resolution: This often involves the sufferer needing to sleep deeply to get rid of the headache.

Recovery: The sufferer may experience symptoms similar to those in the first prodrome phase and feel generally washed out or hung over.

Are there trigger factors for migraine?

The brain of a migraine sufferer is believed to have a lower sensitivity to stimuli and is therefore more likely to become irritated by stimuli than those who do not have migraine. Those who have migraine are much more likely to trigger an attack from their day to day activities than those who don't have migraine. It is not always easy to recognise triggers as in isolation they often do not cause a migraine attack. However several together may trigger an attack but these need not be the same triggers for each attack. Some common triggers are: food, changes in routine, travel, emotions, too much/too little sleep, menstruation, weather.

How is migraine diagnosed?

Diagnosis is made from taking a thorough history of your condition. Your story gives the clues to what your headache is and often investigations are not necessary and are usually unhelpful.

What is the treatment for migraine?

It is not possible to cure migraine but there are effective treatments to help control them. Treatment involves several steps and includes a diet & lifestyle assessment. This is a very important part of treatment and involves assessing whether any aspects of your lifestyle are affecting your migraines. A stable lifestyle pattern is less likely to trigger a migraine. Drug treatments can either be acute medication which you take when you get an attack or prophylactic (preventative) medication which you take every day to try and reduce the frequency of your attacks.

What type of medication might be prescribed?

Acute medication - this is taken as soon as the headache phase starts. Your GP will discuss the use of acute medication but it could be any of the following:

1. Aspirin 900mg every 4-6 hours or Paracetamol 1.5g every 4-6 hours
2. Ibuprofen 800mg or Diclofenac 100mg or Diclofenac Suppository 100mg
3. Products that contain painkillers and anti sickness drugs e.g. domperamol, migraleve, paramax
4. Triptans – sumatriptan, naratriptan etc.

If nausea is a significant feature of your migraine attacks it is possible to prescribe an anti sickness medication for you.

Preventative medication – this is taken every day to help reduce the frequency of your headaches. These medications will be increased over several weeks or months to avoid side effects and to get to a sufficient dose to be effective. This will take perseverance by you to find the drug that works for you and may require regular visits to your GP in the initial stages to get the right treatment regime. Most people who find that all treatments are ineffective have not taken the drugs for long enough at high enough doses and have not given the drugs the best chance to work. Your GP may prescribe any of the following preventative medication:

1. Beta-blockers e.g. propanolol, atenolol, metoprolol
2. Tricyclic anti-depressants e.g. amitriptyline, dothiepin
3. Pizotifen
4. Anti-epileptics e.g. sodium valproate, gabapentin

How long will I take a preventer like amitriptyline for?

This will be taken indefinitely. Once you have a migraine free period for 6 months then the medication can be tapered off. If you are still exposed to factors causing the headache e.g. stress, then medication will continue until it has passed.

Why is it important to look at diet and lifestyle issues?

Diet and lifestyle assessment is essential and should not be overlooked in favour of tablets. It is important to help you control your migraines and to improve your general health and wellbeing. During your consultation you will have been given a leaflet explaining the sorts of diet and lifestyle changes that can help reduce the risks of an attack occurring. These seem very simple when written on paper but require commitment and persistence to achieve in real life. Most of us know we should drink plenty, eat regularly, and get enough sleep but in practice it can be more difficult to follow these recommendations. These are not short term changes but need to be a determined change of lifestyle for the future. This may have a positive effect on controlling your migraines but also on your general health and well being.

What support is available for migraine sufferers?

As well as your local headache clinic and your GP the following organisations provide information and support:

The Migraine Trust
45 Great Ormond Street
London
WC1N 3HZ

Tel: 01536 461333
www.migraine.org.uk

The Migraine Action Association
Unit 6, Oakley Hay Lodge
Road Business Park
Great Folds Road, Corby
NN18 9AS

Tel: 020 7831 4818
www.migrainetrust.org

Reference/with thanks to the Migraine Action Association, the Headache Clinic Team, Dept of Neurosciences, York District Hospital & Julie Edwards, City Hospital Birmingham

Appendix 12

Frequently asked questions Cluster Headache

What is cluster headache?

These are very painful headaches which last a short time (15 minutes – 3 hours). They occur in groups or clusters up to eight times a day (usually at the same times) and this can go on for 6-8 weeks. The attacks then stop for several months before the next "cluster" starts again.

Who is affected by cluster headache?

This type of headache is comparatively rare, affecting an estimated 0.2% of the population. It occurs mainly in men, with onset usually in their 20's – 30's. A small proportion of sufferers are women and there have been cases of children and young people in their teens having this condition.

How often does a "cluster" happen?

Some sufferers have two or three episodes of this kind a year, while others have gaps of a year or more between "clusters". It is possible to have chronic cluster headache where the headache is continuous without gaps.

What are the symptoms of cluster headache?

The headaches are very painful and regular. They begin with pain behind one eye, which becomes rapidly worse. The pain is often described as searing, excruciating, knifelike or boring into the eye. On the side affected, which is not necessarily the same side in every attack, the eye may become bloodshot and weep and the eyelid may droop. The nostril on the same side may feel blocked up and may water. Unlike other headache types where often people want to lie down and keep still, sufferers of cluster headache will feel more like "banging the head against the wall". They will pace about, move vigorously, quite unable to keep still.

What provokes an attack?

Smoking and alcohol can set off an attack.

What is the treatment for cluster headache?

There are two types of medication used for cluster headache:

- Acute medication – to take for symptom control in an acute attack
- Preventative medication – these are taken on a daily basis to reduce the frequency and severity of attacks

What acute treatment is there for cluster headache?

- Oxygen – 100% oxygen at 7 litres per minute through a firm plastic mask for 10-20 minutes. The patient should sit leaning forward with the mask firmly over the face. Any holes in the mask should be taped over. The oxygen cylinders are available on prescription from the NHS but a special valve is required to deliver the correct rate of flow. This can be purchased from British Oxygen. (For more info contact OUCH UK 0161 272 1702).

- Sumatriptan (Imigran) – 1 x 6mg sub-cutaneous injection at the onset of the attack or 1 x 20mg intra-nasal spray administered into one nostril. For both applications there is a maximum of 2 doses in 24 hours with an interval of at least 2 hours between doses. There is no weekly limit. As a general rule triptans in tablet form do not work quickly enough to bring significant relief.

What preventative treatment is there for cluster headache?

Medications such as verapamil, steroids, ergotomine are used to help prevent cluster headaches. Preventative medications take a while to have any effect and need to be taken for a period of time, even several weeks/months, before any benefit is achieved. They are most effective if taken at a regular time each day. The dose of these tablets is increased gradually by your doctor in order to produce a greater benefit for you but also to reduce the chance of side effects occurring.

H**ow long do I take preventer mediation for?**

You will continue taking preventative medication e.g. verapamil until the cluster breaks then remain on it for a short period afterwards (up to 3 months) and then wean off gradually.

Useful addresses

The Migraine Action Association
Unit 6
Oakley Hay Lodge Road
Business Park
Great Folds Road
Corby
NN18 9AS

Tel: 01536 461333

www.migraine.org.uk

The Organisation for the Understanding of Cluster Headache (OUCH UK)
Northam House
Mountenoy Road
Moorgate
Rotherham
S60 2AJ

Helpline: 0161 272 1702

www.ouch-uk.org

Reference/with thanks to the Headache Clinic Team, Dept of Neurosciences, York District Hospital & Julie Edwards, City Hospital Birmingham, The Migraine Action Association & OUCH UK

Appendix 13

Frequently asked questions
Medication Overuse Headache

What is a "medication overuse headache"?

Any painkiller when taken on a regular basis to treat headache symptoms can, over time, lead to daily headache symptoms developing. This type of headache is called a "medication overuse headache". In non-scientific terms the pain receptor is kept switched **on** by the painkiller rather than being switched **off**. This means that you take more and more painkillers, with increasing frequency but with no effect. Then you try stronger and stronger painkillers all to no avail. The only way to correct the situation is to stop all the tablets. This will allow the pain receptors to reset themselves and respond normally again.

How is this type of headache treated?

The only way of treating this headache is to ***stop all your painkillers***. The thought of stopping all your medication may seem impossible. You may feel that you cannot survive without taking your tablets and that there is no way you can get through the day without them. These are very normal feelings. We understand it is not going to be easy and it is likely that things will get worse before they get better. We also know that stopping all your painkillers is the ***only*** way to change how you feel now. You will be guided through a process of withdrawal from your medication and will be supported in this by the specialist nurse.

Can I take *any* painkillers for my headaches whilst going through the withdrawal phase?

No. Taking painkillers of any sort will simply allow the headache to persist. You must take ***no*** painkillers no matter how bad your headaches get. The specialist nurse will discuss with you other means of helping to control your headache symptoms during this phase e.g. wheat bags, relaxation, alternative therapies, exercise.

Why have I been prescribed an anti-depressant tablet?

Amitriptyline is a commonly used drug for the treatment of headaches. It is called a preventer and is used to prevent headaches occurring. It is prescribed at a very low dose and at this dose does not have an antidepressant effect. It has a muscle relaxant effect which is effective in the treatment of headaches. You will be prescribed amitriptyline at a dose of 10-75mg (possibly up to 150mg).

How long will I need to take amitriptyline for?

All preventer medication like amitriptyline should be tried for a minimum of 3 months up to 6 months to assess how effective it is over time. However if you experience side effects which are intolerable then a different type of preventer may be tried instead.

What are the possible side effects of amitriptyline?

Dry mouth, drowsiness, blurred vision, nausea, constipation, difficulty urinating. It might be possible to decrease the dose to reduce side effects or to change to a different medication.

Why have I been prescribed amitriptyline when I have a medication misuse headache and need to come off all tablets?

This is to help reduce the symptoms of withdrawal that you may experience when you stop taking the medication you have been using to control your headaches. It won't necessarily eliminate all withdrawal symptoms but will take the edge off them. You will begin taking amitriptyline at a very low dose (10mg) and gradually increase up to (30mg) before you stop your medication.

Can I drink alcohol when taking amitriptyline?

Alcohol can enhance the sedative effects of amitriptyline. It is therefore sensible to avoid alcohol whilst taking this medication or keep it to a minimum. It is worth bearing in mind that during the washout phase, painkiller medication **must not** be used. Over indulgence of alcohol can cause a hangover and this is not recommended since it might create the need for painkillers which cannot be taken.

Why have I been prescribed propanolol to help with my medication withdrawal?

Propanolol can help to reduce the jittery type feelings you may experience once you stop your medication.

Can I drink alcohol when taking propanolol?
There is no specific reason to avoid alcohol whilst taking propanolol but it is suggested that you adhere to the governments recommended guidelines:

- Women - 14 units per week
- Men – 21 units per week

(1 unit = ½ pint beer, 1 glass wine/spirits)

How long will I need to take the propanolol for?

Usually this is taken for the washout period only i.e. 8 weeks.

What symptoms might I experience when I come off the medication I have been using to help my headaches?

Nausea/vomiting, difficulty sleeping, knotted stomach, feeling edgy, worsening headaches, bad tempered, irritable, mood swings.

How long will the washout phase last?

A minimum of 8 weeks. It takes time for the receptor to reset itself. If you stop too soon things can relapse

What is the worst time when withdrawing from painkiller medication?

It is difficult to say what your experience will be like as everyone reacts differently. Generally the first two weeks are the worst part of painkiller withdrawal. In weeks 3 and 4 you may begin to have headache free days.

If I feel sick what can I do?

You can take an anti sickness tablet which your GP can prescribe for you.

Will I ever be able to take medication for future headaches?

After 2 months you can be reassessed and your type of headache will then be more clear. If it is a tension type headache it is always best to treat this with methods other than medication e.g. relaxation, wheat bags, alternative therapies, lifestyle issues. Once you have had a medication misuse headache you are susceptible to the effects of medication and should avoid wherever possible. If your underlying headache is migraine then appropriate medication can be prescribed.

Do I have to stop all my medication including tablets not for my headaches?

You only need to stop medication used to relieve pain.

Who will help me come off my tablets?

You will be supported through the whole process by the Specialist Nurse in headache. An action plan will be developed to help you prepare to come off the tablets and then strategies identified to help you through the withdrawal phase. Support from family and friends will be important – talk to them and let them help you too.

What if I still have headaches after the 8 week wash out phase?

After all the painkillers are out of your system, the bodies pain receptors will reset back to there normal levels. This allows the pain gates to open and close normally when you get a headache. Removing all painkillers will either reduce your headache frequency back to its usual level or allow an accurate diagnosis to be made. See your GP or headache nurse if symptoms persist.

How do I avoid developing medication overuse headache?

1. Avoid taking painkillers on more than 2-3 days a week. If you need them more regularly than this see your GP about going onto preventer medications which you take every day to prevent headaches occurring.
2. Try other ways to control your headaches. Follow the diet and lifestyle advice to reduce the number of headaches you have. Find ways to distract yourself e.g. exercise or new hobby
3. Deal with any stress you have in your life. Consider relaxation, yoga, complementary therapies or whatever suits you best. Try to be organised. Don't leave things to the last minute and let those around you share and help in relieving any stress that you face.
4. Take control of your headache don't let it rule you. Find out what contributes to your headaches and take steps to avoid or remove them or how to deal with them more effectively.
5. Take your acute painkillers when you **need** them, but do not take them **"just in case".** Keep a check of how many you are taking.

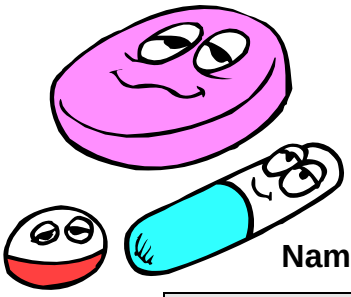
Reference/with thanks to the Headache Clinic Team, Dept of Neurosciences, York District Hospital & Julie Edwards, City Hospital Birmingham

Action Plan

Name:

Washout Schedule **The washout period is 8 weeks. It is important not to take any painkiller medication at all within this 8 week period.**	Comments ***You will have regular follow up from your Headache Nurse Specialist, use this column to write down any notes/reminders from your conversations or follow up appointments.***
Week 1 w/b Date: _____ **This is the first day of taking no painkiller medication at all.**	
Week 2 w/b Date: _____	
Week 3 w/b Date: _____	
Week 4 w/b Date: _____	
Week 5 w/b Date: _____	
Week 6 w/b Date: _____	
Week 7 w/b Date: _____	

Week 8 w/b Date: _____	



Appendix 15

Medication Overuse Headache

Preparation Plan

Name:

Issue	Action
Start Date When is the best time to start? Think about events/activities already planned that may affect start date e.g. Xmas, wedding etc. There may need to be a weaning off period.	Start Dates: Weaning off _____ Washout _____
Support networks Who will support me? Discuss telling friends and family and gathering support for the withdrawal phase.	• • • •
Work Will I need a sick note? Discuss the possibility of taking time off work, visiting GP for sick note, discuss employer support?	
Social Consider social activities? Think about what social engagements are planned or what normal activities you do. It may be helpful to cancel activities in the first few weeks.	
Headache management How will I cope with headaches in withdrawal phase?	• Wheat bags • Relaxation techniques • Alternative therapies • Distraction techniques • Other -
Weaning off medication schedule **Week beginning:** _____ **Reduce tablets by** _____ **Week beginning:** _____ **Reduce tablets by** _____ **Week beginning:** _____	**Preventor Schedule** e.g. Amitriptyline, Nortriptyline, Dothiepin, Sodium Valproate Week beginning: _____ Dose: Week beginning: _____ Dose:

Reduce tablets by _____ **Week beginning:** _____ **Reduce tablets by** _____ **Week beginning:** _____ **Reduce tablets by** _____	Week beginning: _____ Dose: Week beginning: _____ Dose: Week beginning: _____ Dose:

Appendix 16

Complementary therapies Information Sheet

Headache symptoms can be helped by medication and by changes to lifestyle. Some people may also be helped by using complementary therapies. As an NHS service we are unable to recommend any particular therapy or therapist. But the list below gives some examples of the types of complementary therapies available. The relevant organising bodies are listed and they can provide information about local therapists. It is also possible to find therapists through an NHS directory www.complementaryalternatives.com.

The Royal College of Nursing (www.rcn.org.uk) provides a consumer checklist to help with the choice of a therapist. The following questions may be useful:

- *What are their qualifications and how long was their training?*
- *Are they a member of a recognised, registered body, with codes of practice?*
- *Can they give you the address and telephone number of this to check?*
- *Is the therapy available on the NHS?*
- *Is this the most appropriate complementary medicine for your problem?*
- *Are your records confidential?*
- *What is the cost of the treatment?*
- *How many treatments should you expect to need?*
- *What insurance cover does the therapist have?*

Acupuncture

- is an ancient system of healing practised in China for thousands of years. It involves the insertion of fine sterilised needles into various parts of the body to treat a wide variety of conditions. It is said to increase the body's release of natural painkillers, has positive effects on the nervous system and general well being and can encourage the patient's body to heal and repair itself.

Contact: British Acupuncture Council Tel: 020 8735 0400 www.acupuncture.org.uk

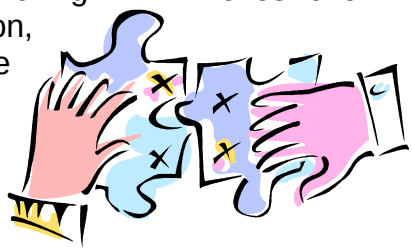
Aromatherapy

- is the systematic use of essential oils in treatments to improve physical and emotional well being. The natural plant oils are used in massage, in the bath and can be inhaled. They are readily absorbed through the skin and have powerful physiological effects.

Contact: Association of Physical & Natural Therapists Tel: 0845 345 2345 www.apnt.org

The Bowen Technique

- is a hands on but gentle therapy. Bowen uses rolling moves over various points of the body which encourage relaxation, realignment and healing. The gentle moves stimulate energy flow promoting the body's own self-healing resources to restore balance; facilitate lymphatic drainage of toxins; promote good circulation; release tension and increase mobility.



Contact: European College of Bowen Studies Tel: 01373 461873 www.thebowentechnique.com

Reflexology

- uses pressure on points in the feet and hands which correspond to all parts of the body. Stimulation of these points improves circulation, balances and relaxes the body, evoking a sense of well-being and thus promoting healing.

Contact: Association of Physical & Natural Therapists Tel: 0845 345 2345 www.apnt.org

Massage Therapy

- uses light stroking, strong kneading, friction and tapping movements to relax and tone up the body's muscles. Each treatment is specific to the patient and is intended to assist in the self-healing process.

Contact: Association of Physical & Natural Therapists Tel: 0845 345 2345 www.apnt.org

Indian Head Massage

- is a totally non-intrusive massage of head, face, scalp, neck, upper arms, shoulders. The treatment is given while sitting in a chair. Oil may be used on the scalp. Indian head massage can be performed anywhere and is helpful for a range of disorders.

Contact: Institute of Indian Head Massage Tel: 01753 831841
www.indianheadmassage.org

Appendix 17

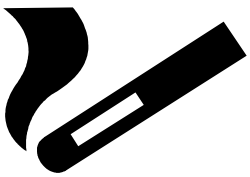
As well as treating your headache symptoms with medication it is also important to think about aspects of your lifestyle that may be affecting your headaches.

Diet
- Eat a cereal/oat based breakfast to give a slow release of sugar
- Do not go for long periods without food – to avoid low blood sugar levels
- Limit intake of caffeine – tea, coffee, fizzy drinks including coca cola
- Eat balanced meals including 5 portions of fruit & vegetables per day

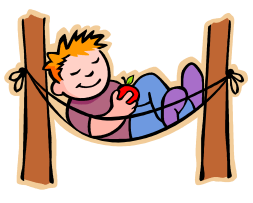
Alcohol
Keep alcohol intake to recommended levels:
- Men 21 units
- Women 14 units

I unit = ½ pint of beer, 1 glass of wine/spirits

Water
- It is recommended that we drink 2 litres (8 large glasses of water/day)
- Drinking too little water can lead to tiredness, lethargy, headaches, inability to concentrate, dry/cracked skin and low blood pressure.
- Coffee, tea, alcohol and related products can cause headaches
- Coffee, tea and alcohol are diuretics and therefore cause more water loss
- Take a bottle of water to work/school/university – keep sipping



Smoking
- Use your local NHS service to help you stop. Nicotine treatment (e.g. gum, patches, lozenges etc) all available on prescription.
- Call the local service based in Hull with clinics available near where you live/work **0800 915 5959**



Sleep
- Try & maintain a regular time of going to bed
- Ensure you have a period of wind down before going to bed
- Avoid working at a computer close to bedtime
- Think about your pre bed routine
- Try to have the same amount of sleep – do not under or over sleep

Posture & eyesight
- Avoid slouching in front of the TV
- Check your position in front of the computer, the VDU should be at eye level
- Do not sleep with too many pillows
- If you have problems with vision see an optician for a check up
- If you have a pre existing visual condition ensure you have regular check ups
- Check your driving position

Appendix 18 Headache Diary

Use this diary to record the days that you have a headache. Cross off each day you have a headache. Observe for improvements and a reduction in the number of headaches you experience. Remember this can take time (up to 2-3 months).

e.g. Mar ~~1~~ 2 3 4 5 6 7 8 ~~9 10~~ 11 12 13 ~~14~~ 15 16 17 18 19 20 ~~21 22~~ 23 24 25 ~~26~~ 27 28 29 30 31 Total: 7

Month																															Total in month
Jan	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Feb	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29			
Mar	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Apr	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30		
May	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Jun	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30		
Jul	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Aug	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Sep	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30		
Oct	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Nov	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30		
Dec	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	

Appendix 19

Relaxation
A deep breathing technique

Breathing slowly and deeply helps to reduce tension in the body. This in turn can help to reduce some of the pain caused by headaches. Deep breathing involves the following three steps:

1. Take a long slow breath **OUT**, emptying your lungs completely.

2. Take a long slow breath **IN**:

- Breathe in through your nose. Pull the air right down into your lungs so that your stomach rises.

- Make this deep breath in last for 3 seconds, count to yourself "one thousand….two thousand….three thousand" as you do this. This will make sure that you are breathing in slowly enough.

- To make sure you are breathing in deeply, place one hand on your stomach and one hand on your chest – you should feel the hand on your stomach move up as you breathe in.

3. Take a long slow breath **OUT**.

- Make this deep breath in last for 3 seconds, count to yourself "one thousand….two thousand….three thousand" as you do this.

- Counting like this will ensure that each in and out breath cycle takes 6 seconds, producing a breathing rate of 10 breaths per minute.

Getting this sort of breathing right will take quite a bit of practice. That's why it is important to practice it regularly. It is also important to practice when your headache is not so severe, so that when it is at its worst, this type of breathing will be easy for you to do and you will be able to use it to better control your headache.

Reference/with thanks to the Headache Clinic Team, Dept of Neurosciences,
York District Hospital.

Appendix 22

GP Management Plan
Cluster Headache

Your patient _____ attended the headache clinic on

_____ and a diagnosis of **Cluster Headache** was made.

The diagnosis of Cluster Headache was discussed with the patient and a patient education leaflet given to them (copy enclosed). The leaflet includes a diary for the patient to record cluster headache episodes. The patient has been advised to make an appointment with you to discuss further management.

This information concentrates on the medical management of Cluster headache:

Acute treatment

Oxygen 100% oxygen at 7 litres per minute through a firm plastic mask for 10-20 minutes. The patient should sit leaning forward with the mask firmly over the face. Any holes in the mask should be taped over. The oxygen cylinders are available on prescription from the NHS but a special valve is required to deliver the correct rate of flow. This can be purchased from British Oxygen. (For more info contact OUCH UK 0161 272 1702).

Sumatriptan (Imigran) 1 x 6mg sub-cutaneous injection at the onset of the attack or 1 x 20mg intra-nasal spray administered into one nostril.

For both applications there is a maximum of 2 doses in 24 hours with an interval of at least 2 hours between doses. There is no weekly limit. As a general rule triptans in tablet form do not work quickly enough to bring significant relief.

Preventative treatment

Verapamil Initially 40mg twice daily increasing over 7-10 days until an effective prophylactic dose is reached, not exceeding a maximum of 120mg 3-4 times daily. Continue for the usual duration of the cluster plus a further 2-4 weeks, then gradually reduce the dose over 2-4 weeks. If the attacks break through increase the dose until control is maintained and reduce again at 2 week intervals.

Steroids Prednisolone enteric coated 60mg daily until control achieved, and then for a further 2 weeks. Then reduce dose gradually over 2-3 weeks. Reduce by 5mg every 3 days until off completely. If the headache recurs during the withdrawal process increase the steroid to the previous dose that kept the patient headache free and continue at that dose for 2 weeks prior to withdrawing as detailed previously.

Ergotomine This can be used on an intermittent basis for patients with short cluster bouts (not recommended for chronic sufferers). Half to one cafergot suppository (1-2mg) 1-4 hours before expected attack e.g. for use at bedtime for night time attacks. Continue only for the duration of the cluster and no longer than 6-8 weeks if tolerated.

Other possible alternatives are the unlicensed use of lithium or sodium valproate but these are not recommended without direct specific contact with the GPwSI/Neurologist.

References/with thanks to:

The Migraine Action Association

Useful addresses

The Migraine Action Association
Unit 6
Oakley Hay Lodge Road
Business Park
Great Folds Road
Corby
NN18 9AS

Tel: 01536 461333

www.migraine.org.uk

The Organisation for the Understanding of Cluster Headache (OUCH UK)
Northam House
Mountenoy Road
Moorgate
Rotherham
S60 2AJ

Helpline: 0161 272 1702

www.ouch-uk.org

A summary of the 1st GP Questionnaire
Headache referral and management

The first questionnaire asked GPs to give information about where they referred patients with symptoms of headache before May 2004 (the headache clinic was not established at this time). They were then asked to rate the service that their patient received. The answers to the questions below therefore relate to a number of different services provided within the geographical area covered by YWCPCT and SWRPCT. The questionnaire was distributed on 1st September and the last return date was 1st October 2004 although the majority were returned in September. 198 questionnaires were sent and 118 were returned = 60% return rate.

To which main hospital are you geographically closest?
Of the GPs that responded 41% (48) indicated this was Scarborough while 17 % (20) indicated that it was Bridlington. 14% (17) stated they were nearest Hull, 9% (11) York and 5% (6) were nearest to Whitby. The rest 13% (15) indicated they were equidistant between 2 sites 1% (1) gave no answer.

How satisfied have you been with the service the patient received?
53% (63) were satisfied and 13% (15) indicated they were very satisfied with the service their patient received. 9% (11) were not satisfied, 4% (5) were not at all satisfied, 19% (14) gave no opinion 7% (9) gave no answer and 1% (1) ticked more than one option.

Are you content with the written information that is given to the patient regarding the diagnosis of headache and the suggested management following a specialist assessment?
30% (35) were content, 15% (18) were very content and 13% (15) were fairly content with the written information the patient received however 39% (40) were not aware that any information had been provided. 1% (1) was not content and 1% (1) was not at all content. 7% (8) gave no answer.

Are you content with the written information provided to you (GP) regarding the patient's diagnosis of headache and the suggested management after a specialist assessment?
47% (55) of GPs are content with the written information that they are provided with the rest are either very content, 19% (22) or fairly content, 19% (23), 0% (0) indicated that they were not or not at all content and 15% (18) gave no answer.

How confident are you in managing a patient with headache?
64 (54%) indicated that they were fairly confident in managing headache with 40 (39%) stating that they were confident. Only 7 (6%) indicated that they were very confident while 6 (5%) indicated that they were not confident in managing headache. 0% (0) indicated that they were not at all confident and 1% (1) gave no answer

A summary of the 2nd GP Questionnaire
GPwSI Headache Service

A second questionnaire was distributed in January and GPs were asked about referrals made to the GPwSI clinic and to rate their satisfaction of the service. 198 questionnaires were distributed and 108 were returned = 55% return rate.

Have you referred patients to the GPwSI clinic in Bridlington?
Of the returns 41% (44) had referred to the GPwSI clinic and 59% (64) had not.

If you have not referred please indicate the reason why you have not made any referrals?
Of those 64 GPs who had not referred to the clinic 69% (44) indicated that the reason was that they had not seen any suitable patients, 17% (11) that there was a more convenient location provided elsewhere and 14% (9) that there was another reason (including not being aware or forgetting about the service, being on maternity leave during the period the headache clinic was running, being an ex-anaesthetist with pain clinic experience, being unaware that it was rapid access or stating that they manage such patients themselves).

Approximately how many patients have you referred?
Of the 44 GPs that had referred to the clinic 66% (29) had referred 1-2 patients, 32% (14) referred 3-5 and 2% (1) referred 6-10. No GP had referred over 10 patients.

In general how satisfied have you been with the service the patient (s) received?
Of the 44 GPs that had referred patients 45% (20) were very satisfied, 45% (20) were satisfied, 5% (2) were not satisfied, 0% (0) were not at all satisfied, 2% (1) had no opinion because as the time of the questionnaire they had only just referred a patient and 2% (1) GP indicated that the satisfaction varied according to the patient referred.

Have you been content with the written information that has been given to the patient(s) after their appointment?
Of the 44 GPs that had referred patients 25% (11) were very content, 41% (18) were content, 5% (2) were fairly content, 0 were not content, 0 were not at all content, 27% (12) were not aware of the information that had been given, 2% (1) gave no answer.

Have you been content with the written information you have received after the patient has been seen?
Of the 44 GPs that referred 50% (22) were very content, 41% (18) were content, 7% (3) were fairly content, 0% (0) were not content, 0% (0) were not content at all and 2% (1) was not aware of the information they have been given.

Have you used and implemented the suggested management plan the patient (s) was issued with after a specialist assessment
Of the 44 GPs 75% (33) said yes they had for all patients, 11% (5) said they had for some of the patients. 11% (5) indicated that they had not implement the management plan for any of the patients and 3% (1) gave no answer

If you have not implemented the management plan please indicate a reason.
Of the 10 GPs that had not implemented management plans 20% (2) indicated that this was because the patient had not returned to the surgery, 10% (1) indicated that the management plan was an inappropriate suggestion as the patient was intolerant of suggestive dose regime (in part) 50% (5) gave no answer and 20% (2) indicated that the headache had resolved by the time the patient had returned to the surgery.

NB. The specialist nurse has followed up some patients who have indicated that they either have not been back to the surgery/or that the GP has not implemented the management plan. In all cases that have been followed up these issues have been resolved by this communication but there is an awareness that further work would be needed to ensure that all patients management plans are implemented.

Have the information leaflets/management plans that you have received made you more confident in managing headache?
Of the 44 GPs that referred 55% (24) indicated that the information leaflets and management plans distributed had increased their confidence, 30% (13) indicated that they had not, 4% (2) indicated that this question was not applicable (1 of these stated that this was because it was too early to say) and 11% (5) gave no answer.

How confident do you currently feel in managing patients with symptoms of headache?
Of the 44, 7% (3) were very confident, 36% (16) were confident, 57% (25) were fairly confident, 0% (0) were not confident, 0% (0) were not at all confident.

Other comments
Positive feedback

- The suggested management is just how I would have managed them myself. This is a very good service.
- The leaflets have only made me more confident in managing the patients that I referred.
- This is an excellent service. It is still hard to get patients to stick to long term management plan and have patience but written plans help.
- It's great to have a service with a sensible waiting time to appointment
- It does provide a useful alternative to very long wait for consultant clinics
- It is an excellent service both for us and for our patients, congratulations for all your hard work and initiative
- A very good service, the patient liked it a lot, it's a great support for primary care and provides very good educational feedback

Improvement areas

- The majority of patients referred are not seen on follow up. Which I sometimes would find helpful especially in the ones with codeine induced headaches to help compliance and reassurance. Apart from that it is very helpful to have those diagnosis confirmed when suspected.
- A patient who ultimately was diagnosed with temporal arteritis had a long delay waiting for a biopsy and then the result took far too long to be acted upon.
- GPs often refer headaches when they know there is not an organic cause but when the patient will not accept this. This is a very expensive use of resources.
- The waiting time for appointment is too long
- I don't think that it added anything to the patient's management. It possibly reassured me but I'm not sure if the patients were reassured.
- The clinic has led to the removal of direct access CT scan and MRI for headache. The clinic should not be funded as a GPwSI from enhanced services as not all GPs can provide bid for the service.
- I do not like having to use a referral proforma

Appendix 25

GPwSI contract & costs

Contract = equivalent to GP salary point 05 at £80717
Based on 10 PA per week pro rata £80717/10*1.5 = £14,649 including on costs 21% (14% superann, 7% NI) + inflation increase 3.225% = £472 + £14,649 =£15,121

Location	Originally Bridlington District Hospital to move to Driffield and Malton community Hospital
Employer	Yorkshire Wolds and Coast PCT
Medical Negligence responsibility	Yorkshire Wolds and Coast PCT
PA	4 hours
Contracted sessions	78
No. of clinical sessions	41
No. of educational sessions to primary care	4 (2 YWCPCT/2 SWRPCT)
No. of refresher sessions – CPD (I session every 3 months/development focussed)	4 (Neurology clinic - Scarborough)
No. of CPD sessions – general conference	5
No. of admin/audit sessions	15
No. of holidays	9
No. of sessions per week	1.5
No. of new patients per session	7

Remuneration will be based on a contract of £15,121 for 78, 4hr PA per annum, including 9 paid sessions for annual leave. This includes 41 for clinical work, 4 for educational sessions to primary care, 4 refresher sessions with the Neurology team at Scarborough, 5 sessions for CPD attendance at conferences and 15 for administration/audit work.

On a sessional basis the rate £15,121 equates to:
£193.60 per contracted PA (£15,121/78)
£219.10 per activity related PA (£15,121/69) excluding annual leave
£236.30 per clinical PA (£15,121/64) excluding annual leave and CPD

Future years would increase due to inflation at 3.225% per year.